National Library of Canada

Acquisitions and Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale du Canada

Direction des acquisitions et des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

UNIVERSITY OF ALBERTA

CAREGIVER BURDEN
IN RELATION TO INCONTINENCE IN THE ELDERLY

BY

KATHLEEN D. DALY

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND
RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR
THE DEGREE OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

FALL, 1993

National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-88241-7

Canada

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: Kathleen D. Daly

TITLE OF THESIS: Caregiver Burden in Relation to Incontinence in the Elderly

DEGREE: Master of Nursing

YEAR THIS DEGREE WAS GRANTED: 1993

Permission is hereby granted to the University of Alberta Library to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as hereinbefore provided neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.

Kathleen Daly

Kathleen Daly
48 Wahstao Crescent
Edmonton, Alberta
T5T 2W8

September 30, 1993

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, a thesis entitled CAREGIVER BURDEN IN RELATION TO INCONTINENCE IN THE ELDERLY submitted by KATHLEEN DALY in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

Dr. Dana Hames Wertenberger

Dr. Anne Neufeld

Dr. Norah Keating

September 22, 1993

I dedicate this work to
Peter, Terry, Maureen, Kevin, and Janet.
Their confidence in me never wavers.

ABSTRACT

Although care receiver incontinence has been related to increased caregiver burden and subsequent institutionalization, very little research has examined incontinence specifically and what aspects of this stressor may be specifically related to these outcomes. Using the framework outlined by Zarit, this study attempted to identify factors that affect a caregiver's perception of incontinence as a burden. Using a structured questionnaire, interviews were conducted with 43 caregivers of elderly individuals who were incontinent of urine and/or required assistance with their toileting to prevent them from being incontinent of urine. Data were analyzed for possible associations between the identified factors and the Burden Interview.

Although the caregivers interviewed were moderately to severely burdened by their caregiving responsibilities, there was no aspect of the care receiver's incontinence that was significantly associated with this perceived burden. The burden being experienced may have been related to the incontinence or to other aspects of the caregiving situation. The caregivers interviewed did not view the care receiver's incontinence as a "serious problem" or consider it a reason to institutionalize the care receiver. However, incontinence may play a role in the decision to institutionalize as the level of perceived burden being experienced by the caregiver increases. Caregivers indicated that their decision to continue providing care to the care receiver was more dependent on the maintenance of their own health then on any particular care receiver problem.

I would like to acknowledge the expertise and support freely given
by my supervivor, Dr. Dana Hames Wertenberger;
my committee, Dr. Anne Neufeld and Dr. Norah Keating;
and my colleagues at the University of Alberta Hospitals
School of Nursing.

Table of Contents

Introduction....1
Significance of the Study....4
Purpose of the Study....5
Operational Definitions....5
Review of the Literature....7
Stress and Caregiving....7
Contextual features....7
Stress process....11
Stressors....11
Secondary stressors....13
Mediators of stressors....14
Secondary appraisal....14
Outcomes....15
Caregiving Stress and Incontinence....16
Summary....17
Methods....20
Design....20
The Sample....20
Procedure....20
Identification of population....20
Recruitment of sample....21
Methods and Instruments....21
Data collection....21
Demographic questionnaire....22
Research questionnaire....23
Validity....25
Field notes....26
Data Analysis....26
Ethical Considerations....27
Limitations....28
Findings....29
Description of the Care Receivers....29
Care receiver and caregiver demographics....29
Care receiver physical and self-care abilities....31
Care receiver cognitive ability....32

Caregiver supervision of care receiver....33
Care receiver incontinence....33
Description of the Caregivers....34
Caregiver demographics....35
Caregiver/care receiver living arrangements....35
Caregiver education....37
Caregiver employment status....37
Caregiving history....37
Caregiver health....37
Informal support to caregiver....38
Formal support to caregiver....39
Caregiver appraisal of incontinence....39
Caregiver Response to Burden Interview....40
Relationship of Burden Interview to Identified Variables....44
Relationship between burden and contextual features....44
Relationship between burden and objective stressors....45
Relationship between burden and subjective indicators of stress....48
Relationship between burden and mediators of stress....49
Summary....50
Discussion....52
Relationship Between Caregiver Burden and Care Receiver Incontinence....52
Research Limitations....53
Summary....54
Relationship Between Care Receiver Incontinence and Institutionalization of Care Receiver....55
Caregiving and the Maintenance of Caregiver Health....57
Relationship of Findings to Framework....62
Implications for Nursing and Future Research....62
Summary and conclusions....66
References....68
Appendix A....77

Appendix B.....79
Appendix C.....82
Appendix D.....85
Appendix E.....90

List of Tables

Table	Description	Page
1.	Demographics: Care Receiver and Caregiver	30
2.	Care Receiver Physical and Self-Care Ability	32
3.	Living Arrangements: Caregiver and Care Receiver	36
4.	Caregiver Response to Burden Interview	41
5.	Correlation Between Burden Interview Summed Score and Specified Contextual Features (n=43)	45
6.	Correlation Between Burden Interview Summed Score and Caregiving Stressors (n=43)	46
7.	Correlation Between Burden Interview Summed Score and Stressor Incontinence (n=43)	47
8.	Correlation Between Burden Interview Summed Score and Caregiver Appraisal of Stressor Incontinence(n=43)	48
9.	Correlation Between Burden Interview Summed Score and Informal Support(n=43)	49
10.	Correlation Between Burden Interview Summed Score and Formal Support(n=43)	50

List of Figures

Figure	Description	Page
1.	An Expanded Framework for Caregiving	2
2.	Operational framework	18
3.	Operational framework indicating where research supports Expanded Framework for Caregiving	63
4.	Theoretical framework indicating where research supports Expanded Framework for Caregiving	64

Introduction

What is the relationship between a primary caregiver's perception of subjective burden and factors associated with caring for a dependent elder who is incontinent? Research over the past decade has recognized the sometimes stressful nature of family caregiving in relation to the long-term care of older persons. One frequently identified source of increased stress or burden experienced by caregivers is that of caring for an individual who is incontinent. This study will attempt to identify factors that have predictive value in determining whether a caregiver will perceive incontinence as a source of burden or stress.

Many researchers over the past decade have documented the fact that being a family caregiver can be very stressful, placing increased burden/strain on the caregiver (Baines, 1984; Bunting, 1989; George & Gwyther, 1986; Pearson, Verma & Nellett, 1988; Quayhagen & Quayhagen, 1988; Robinson, 1989; Worcester & Quayhagen, 1983; Zarit, Reeves & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986). Researchers have examined the relationship between caregiver burden and various attributes of the caregiver, care receiver, and environment. Studies document possible relationships between caregiver burden and the degree of functional impairment of caregiver and care receiver, cognitive impairment of care receiver, and social support available to the caregiver (Baines, 1984; George & Gwyther, 1986; Pearson, Verma & Nellett, 1988; Quayhagen & Quayhagen, 1988; Robinson, 1989; Worcester & Quayhagen, 1983; Zarit, Todd & Zarit, 1986).

Most caregiving research has been guided by a stress and coping paradigm that is basically linear in design. The caregiver is faced with stressors, which are mediated by psychological processes such as appraisal, social support, and coping strategies, and result in outcomes such as subjective burden and decreased well being (Gatz, Bengtson & Blum, 1990; Vitaliano, Maiuro, Ochs & Russo, 1989; Zarit, 1989; Zarit, 1992; Zarit, Birkel & Malonebeach, 1989). Using this framework, common stressors have been identified, although the stress and burden experienced by family caregivers has been found to be individually variable, with a number of mediators affecting the relationship between stressors on the caregiver and outcomes. Based on his own research and drawing on the work of Pearlin, Semple & Turner (1989), Zarit (1992) has

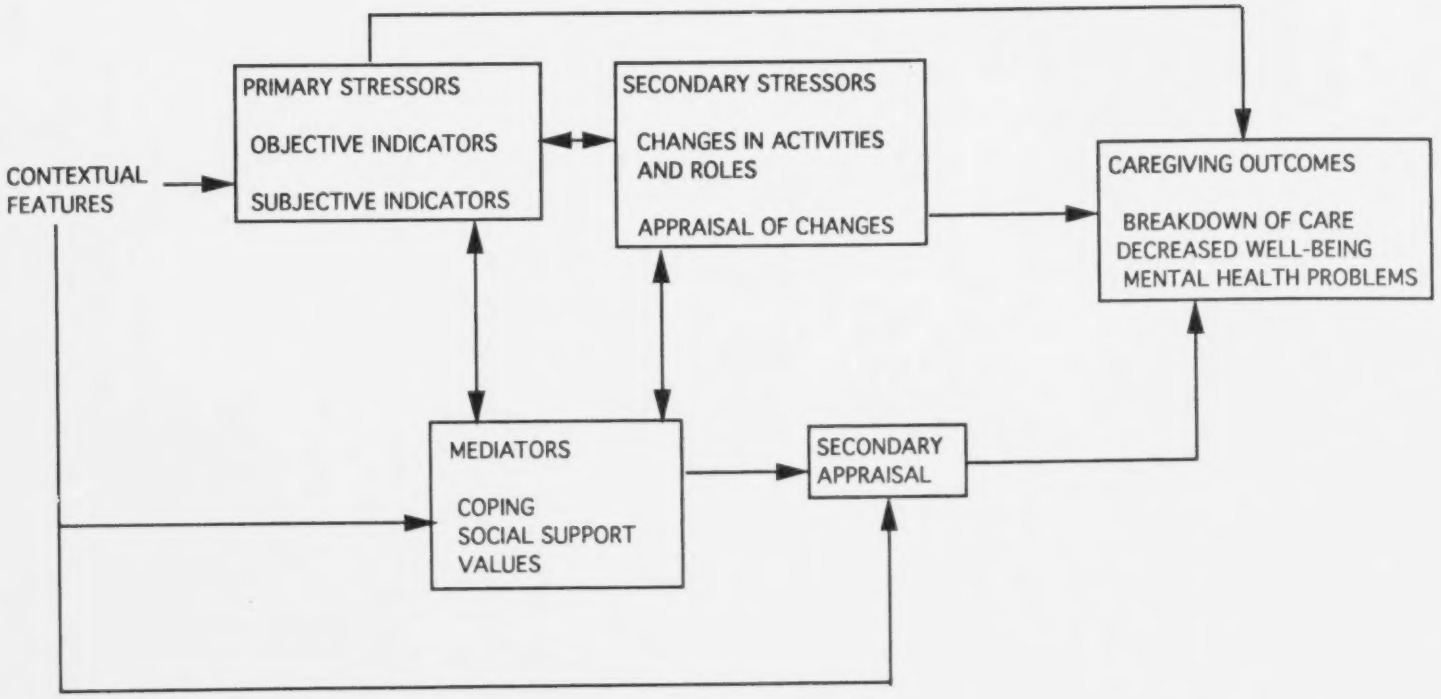

Figure 1
An Expanded Framework for Caregiving (Zarit, 1992)

conceptualized a general framework for caregiving in two parts: contextual features and the stress process model (Figure 1). This framework allows for the consideration of the specific family context and the sociocultural context in which caregiving occurs, which are identified as limitations of the stress and coping paradigm (Zarit, 1992).

One of the functional impairments frequently cited as increasing caregiver burden is urinary incontinence (Baines, 1984; Brink, Wells & Diokno, 1983; Chenoweth & Spencer, 1986; Given, King, Collins & Given, 1988; Heller, Whitehead & Johnson, 1989; Jones & Vetter, 1984; Noelker, 1987; Noelker & Bass, 1989; Schirm, 1989; Snyder & Keefe, 1985; Zarit, Todd & Zarit, 1986). The occurence of urinary incontinence is a well documented phenomenen in the geriatric population. The prevalence of urinary incontinence in the over sixty-five population has been estimated to vary from 5-15% in community living individuals and range to 40-50% for hospitalized and institutionalized persons (Diokno, Brock, Brown & Herzog, 1986; Harris, 1986; Herzog & Fultz, 1990; Kok,Voorhorst, Burger, Houten, Kenemans & Janssens, 1992; Mohide, 1986; Mohide, Pringle, Robertson & Chambers, 1988; Ouslander, 1992; Palmer, 1988; Sier, 1988; Teasdale, Taffet, Luchi & Adam, 1988). Urinary incontinence is identified as one of several factors cited when caregivers seek institutionalization (Brink, Wells & Diokno, 1983; Chenoweth & Spencer, 1986; Dobson, 1974; Hu, 1990; Knopman, Kitto, Deinard & Heiring, 1988; Lund, Pett & Caserta, 1987; O'Donnell, Drachman, Barnes, Peterson, Swearer & Lew, 1992; Ory, Wyman & Yu, 1986; Palmer, 1988; Snyder & Keefe, 1985; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Vetter, Jones & Victor, 1981; Williams & Pannill, 1982; Worcester & Quayhagen, 1983).

Care receiver incontinence has been related to increased caregiver burden/strain and subsequent institutionalization of the care receiver. However, no research was found that examined those factors in the caregiver, care receiver, or caregiving situation that affects the decision to institutionalize the care receiver. It has been this researchers professional experience in working with elderly clients that incontinence is a caregiving issue. In both community and hospital settings, incontinent care receivers may require assistance with its management, but caregivers do not see this as a factor they are unable or unwilling to

manage. Incontinence has not been seen as a reason for discontinuing the care of their relative. Using the framework outlined by Zarit (1992) this study attempted to identify factors that affect a caregiver's perception of incontinence as a subjective burden.

Significance of the Study

The number of elders residing in the community is increasing, due to a proportional increase of elders in the general population. There is an increased prevalence of chronic disease in this population, a trend toward earlier discharge from hospital, a trend toward increased levels of community based care, and increased waiting time prior to institutional placement. These mean that we can anticipate more informal caregivers will be caring for dependent elderly who are incontinent in the community setting (Killeen, 1989; Van Ort & Woodtli, 1989). A majority of elders express a desire to be self-sufficient, but in times of need it is primarily the family to whom they turn (Killeen, 1989). It is informal family caregivers who are the primary source of support for the long-term care of dependent older people living in the community (Caserta, Lund, Wright & Redburn, 1987; Given, King, Collins & Given, 1988; Hasselkus, 1989; Killeen, 1989; Kosberg & Cairl, 1986; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Worcester & Quayhagen, 1983). From the perspective of the elder, family care often means an alternative to institutionalization and provides the opportunity to continue one's life in familiar surroundings (Zarit, 1992).

Potential outcomes of research that studies urinary incontinence and perceived caregiver burden include the identification of predictors of increased burden in relation to urinary incontinence. If it is possible to identify what aspects of urinary incontinence are perceived as most stressful by caregivers, then health care workers can use this information to identify those caregivers most at risk for perceiving their relative's incontinence as a burden. If it is possible to identify what aspects of urinary incontinence are perceived as most stressful by caregivers, then health care workers could consider this information in developing and implementing interventions and programs that address incontinence in the dependent elderly, thus enhancing available support services to clients.

If health care professionals could identify those caregivers most at risk for perceiving that the care of a relative with urinary incontinence is a burden, then interventions to assist them could be focused on those individuals. The result of an improved ability to identify aspects of urinary incontinence which increases subjective burden or those caregivers most at risk of increased subjective burden may be the provision of improved interventions that will assist in maintaining clients in the community setting.

Purpose of the Study

The purpose of this study is to answer the question: Is there a statistically significant relationship between the subjective burden reported by primary caregivers of incontinent dependent elderly and:

1. specified contextual features.
2. objective and subjective attributes of incontinence as a stressor.
3. mediators of incontinence as a stressor.

Operational Definitions

1. Burden reflects the sense that care demands have overwhelmed the person's emotional, physical, and financial resources for providing assistance (Zarit, 1992; Zarit, Birkel & Malonebeach, 1989).
2. Contextual features are those aspects of the caregiving situation that describe the family and sociocultural context in which the caregiving event is occurring. They provide background descriptors which may be related to elements in the stress and coping framework (Zarit, 1992).
3. Stressors are the demands that result from the care receiver's illness and disability. They have an objective and subjective component (Pearlin, Turner & Semple, 1989; Zarit, 1992).

    3a. The objective indicators of the stressor are the specific bahaviors or tasks to which the caregiver responds, an example of which is incontinence and assisting with incontinence (Zarit, 1992).

    3b. The subjective indicators of the stressor are the extent to which caregivers perceive the demands of the specific care task to be disturbing, threatening, overwhelming or manageable, reflecting individual differences in the meaning of the behavior and in the appraisal of threat from same (Zarit, 1992).

4. Mediators of stressors are those factors that have an effect on the impact of the stressors on individual caregivers. Mediators of stressors resulting from caregiving that are noted in the literature include coping strategies and social support (Gatz, Bengtson & Blum, 1990; Pearlin, Turner, Semple, 1989; Zarit, 1992; Zarit, Birkel & Malonebeach, 1989).
5. Secondary stressors are the consequences of providing care on other areas of the caregivers life (Zarit, 1992).
6. Secondary appraisal reflects the process by which people evaluate how adequate their resources are for coping with the threats posed by stressors (Zarit, 1992).
7. Urinary incontinence is the involuntary loss of urine from the bladder.

Review of the Literature

Stress and Caregiving

In the past decade one area of research in gerontology has been on family caregiving. It is well documented that being a family caregiver can be stressful, although considerable individual variability has been noted, and a number of mediators appear to affect the relationship between caregiver stressors and outcomes for both caregiver and recipient.

Most research on caregiver burden has been guided by a stress and coping framework (Lazarus & Folkman, 1984; Pearlin & Schooler, 1978). The elements of these frameworks incorporate 1) the stressor, demands, or life event that the caregiver is faced with, 2) perceptions, appraisals, and attributions about the event and the demands created by the stressor, 3) mediators such as the coping strategies and formal/informal resources that the caregiver draws on, and 4) outcomes for the caregiver such as a sense of subjective strain or burden, emotional and health symptoms (Gatz, Bengtson & Blum, 1990; Pearlin, Turner & Semple, 1989; Zarit, 1989; Zarit, 1992; Zarit, Birkel & Malonebeach, 1989).

Zarit (1992) noted that this approach does not take into account the specific family context or the larger sociocultural context in which the caregiving occurs. He proposes an expanded framework for caregiving that is divided into two parts; contextual features and stress process model of caregiving (Figure 1) (Zarit, 1992).

Contextual features

Contextual features are those aspects of the caregiving situation that describe the family and sociocultural context in which the caregiving is occurring (Zarit, 1992). They provide background descriptors to which outcomes and observations may be related. Zarit (1992) lists contextual issues that have been identified in the family caregiving literature as related to subjective caregiver burden. These include age, gender, caregiver relationship to care receiver, household composition, caregiver education, caregiver employment, caregiving history, and caregiver health.

Age of either the caregiver or care receiver and its relationship to caregiving outcomes has produced variable findings. In those studies where researchers have reported a relationship between caregiver age and caregiving outcomes, the caregiver's age has been related to the decision

to institutionalize care receivers, with younger caregivers choosing this alternative more frequently (Vitaliano, Maiuro, Ochs & Russo, 1989; Colerick & George, 1986). Related to this, Worcester & Quayhagen (1983) reported that older caregivers experience greater situational satisfaction with caregiving. Others have found that caregiver age is not significant in predicting perceived burden of the caregiver or institutionalization of the care receiver (Fitting, Rabins, Lucas & Eastham, 1986; Hirschfeld, 1981; Hirschfeld, 1983; Pratt, Schmall & Wright, 1986; Pratt, Schmall, Wright & Cleland, 1985; Pratt, Wright & Schmall, 1987). The relationship of the caregiver to the care receiver, spousal caregivers being generally older, may be the dimension that is being reflected when age of the caregiver is related to caregiving outcomes.

Caregiver gender and its relationship to caregiving outcomes has also produced variable findings. Caregivers in all studies are predominently female, although a significant number of spousal caregivers are male (Stone, Cafferata & Sangl, 1987). In those studies that included male caregivers some found gender to be predictive of subjective feelings of burden in caregivers, with younger female caregivers reporting higher levels of burden and subsequent relinquishing of care (Colerick & George, 1986; Pruchno & Resch, 1989; Zarit & Zarit, 1982). Others found gender nonsignificant (Fitting, Rabins, Lucas & Eastham, 1986; Pratt, Schmall & Wright, 1986; Pratt, Schmall, Wright & Cleland, 1985; Pratt, Wright & Schmall, 1987; Zarit, Todd & Zarit, 1986). The relationship of the caregiver to the care receiver, most male caregivers also being spouses, and spousal caregivers being less likely to relinquish care, may be what is reflected in these studies.

The caregiver's relationship to the care receiver appears to be an important dimension in predicting perceived burden and caregiving outcomes. Some studies have found considerable differences in the amount of strain and distress reported by caregivers, depending on whether they are the husband, wife, adult child, or other relative of the care receiver (Cantor, 1983; Colerick & George, 1986; George & Gwyther, 1986; Johnson, 1983; Johnson & Catalano, 1983; Lund, Pett & Caserta, 1987; Nygaard, 1988; Pruchno & Resch, 1989; Zarit & Zarit, 1982), while others found that the relationship of the caregiver to the

care receiver was nonpredictive (Deimling, Bass, Townsend & Noelker, 1989; Hirschfeld, 1981; Hirschfeld, 1983; Knopman, Kitto, Deinard & Heiring, 1988; Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986). Spouses have generally reported less subjective strain and burden than adult children as caregivers, with adult children tending to have more conflict among competing obligations. Aspects of the quality of the relationship between caregiver and care receiver also appears to contribute to overall feelings of burden (Brody, 1989; Cantor, 1983; Gilleard, Belford, Gilleard, Whittick & Gledhill, 1984; Pratt, Schmall & Wright, 1986; Pratt, Wright & Schmall, 1987; Sheehan & Nuttall, 1988).

Another contextual feature identified in the literature is that of living arrangements or household composition, whether the caregiver is living in the same household as the care receiver, and how many other individuals of which generations reside in the household. Again the findings in relation to this variable are inconclusive. Some studies found that caregivers in shared households reported increased strain and more limitation of activities (Brody, 1989; Deimling, Bass, Townsend & Noelker, 1989; Sheehan & Nuttall, 1988) and others reported that the differences between those living in shared or separate residences was insignificant (Pearson, Verma & Nellett, 1988). Of note, is that the care receiver is often more impaired and requires more assistance and/or supervision in shared residence situations, expecially in those instances where the caregiver is not a spouse or the care receiver (Deimling, Bass, Townsend & Noelker, 1989).

Education, adequacy of income, and employment status are part of the sociodemographic context that defines the contextual features of family caregiving. No studies were found where education was significantly associated with caregiver strain. In relation to this, most studies accessed volunteer samples with relatively homogeneous levels of education making this variable difficult the assess. Higher levels of income have consistently been associated with lower levels of caregiver strain and higher levels of caregiver morale and life satisfaction (Brody, 1989; Fengler & Goodrich, 1979; Birkel, 1987). One study reported finding that lower income persons were more satisfied in the caregiver role but related these findings to the caregiver's relationship to the care

receiver, spouses being more satisfied but having lower incomes (Worcester & Quayhagen, 1983). Employment of the caregiver in the labor force has been associated with increased caregiver strain in some sample populations (Birkel, 1987; Fengler & Goodrich, 1979; Stone, Cafferata & Sangl, 1987) and low levels of caregiver strain in others (Birkel, 1987).

Descriptors of caregiving history become a contextual feature that has been related to caregiver strain. The most frequent measures of caregiving history have been duration of caregiving, hours of caregiving required per day, and changes in either of these over time. Reported findings in studies have varied, with some finding longer duration and increased amount of time per day associated with increased caregiver strain (Baille, Norbeck & Baines, 1988; Cantor, 1983; Nygarrd, 1988; Pratt, Schmall & Wright, 1986; Pratt, Wright & Schmall, 1987; Sheehan & Nuttall, 1988; Snyder & Keefe, 1985), while others reported no significant relationship (Novak & Guest, 1989; Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986).

Caregiver health has been examined as a variable that affects caregiver burden and as an outcome affected by caregiving. Most studies reviewed note that caregivers who reported their own health as poor experienced greater subjective burden in caregiving and more frequently sought institutionalization of the care receiver (Deimling & Poulshock, 1985; Gilleard, Belford, Gilleard, Whittick & Gledhill, 1984; Nygaard, 1988; Pratt, Schmall & Wright, 1986; Pratt, Wright & Schmall, 1987; Pratt, Schmall, Wright & Cleland, 1985). Other studies found no statistically significant relationship between self-rated caregiver health and subjective burden or the decision to continue caregiving (Hirschfeld, 1981; Hirschfeld, 1983; Pruchno, Kleban, Michaels, Dempsey, 1990). Many studies have reported results on health related outcome measures. Schultz, Visintainer and Williamson (1990) reviewed 34 studies that examined caregiving and health related outcomes. These ranged from self-reports of symptoms by caregivers to formal clinical diagnoses. They concluded that the literature on both psychiatric and physical morbidity effects of caregiving is suggestive but not conclusive evidence that there are morbidity effects related to caregiving.

In summary, there are indications that some of the contextual features identified by researchers may be related to caregiver burden and caregiving outcomes but the evidence is far from conclusive. The two features which are cited most frequently as being associated with increased levels of caregiver burden are the caregiver's relationship to the care receiver and the caregiver's health. In looking at the relationship between caregiver burden and other contextual features: age of either the caregiver or the care receiver, caregiver gender, living arrangements , household composition, caregiver education, adequacy of income, employment status, and caregiving history, the findings were more variable and far from conclusive.

Stress process

The stress process as described by Zarit (1992) includes several elements: 1) primary stressors which have objective and subjective indicators, 2) mediators, 3) secondary stressors, 4) secondary appraisal, and 5) caregiving outcomes (Figure 1). This framework guided the researcher in developing the research plan.

Stressors. A substantial literature describes and attempts to measure the various stressors that occur with the caregiver role. Zarit (1992) describes both objective and subjective components to these stressors. The objective component is the specific care task to which the caregiver must respond. The subjective component is the extent to which the caregiver perceives the demands to be threatening, overwhelming or manageable (Gatz, Bengtson & Blum, 1990; Pearlin, Turner & Semple, 1989; Zarit, 1989; Zarit, 1992).

The objective indicators of the stressors have been characterized along a number of dimensions: the particular illness, presence or extent of cognitive deficits, types of functional problems or difficulties in self-care, and special management problems (Gatz, Bengtson & Blum, 1990; Williams & Gaylord, 1990, Zarit, 1992). Caregiving tasks are typically assessed by measures of activities of daily living and quantified in terms of categories of assistance, amount of help required with activities of daily living, and amount of time required for meeting the elders need for care. A variety of tools have been developed by researchers and practitioners to facilitate description and measurement of care receiver needs and caregiver tasks. These include the Memory and Behavior

Problem Checklist (Zarit, Orr & Zarit, 1985), the Instrumental Activities of Daily Living Scale and Physical Self-Maintenance Scale (Lawton & Brody, 1969), the OARS Multidimensional Functional Assessment Questionnaire (Fillenbaum, 1988), and the Alberta Assessment and Placement Instrument for Long Term Care (Alberta Health, 1989).

In addition to describing the help provided, researchers have attempted to identify the most difficult aspects of caregiving by relating stressors to outcomes and consequences of caregiving. While some studies have found no significant relationship between identified care receiver characteristics or demands and outcomes of caregiving (Fengler & Goodrich, 1979; George & Gwyther, 1986; Haley, Levine, Brown & Bartolucci, 1987; Hirschfeld, 1981; Hirschfeld, 1983; Novak & Guest, 1989; Zarit, Reever & Bach-Peterson, 1980), other studies have identified such relationships. The indicators most often associated with increased sense of caregiver stress or burden are the presence and extent of cognitive impairment and disruptive behavior in the care receiver (Baille, Norbeck & Barnes, 1988; Deimling & Bass, 1986; Deimling, Bass, Townsend & Noelker, 1989; Gilleard, Belford, Gilleard, Whittick & Gledhill, 1984; Lund, Pett & Caserta, 1987; Moritz, Kasl & Berkman, 1989; O'Donnell, Drachman, Barnes, Peterson, Swearer & Lew, 1992; Pearson, Verma & Nellett, 1988; Pratt, Schmall & Wright, 1986; Pratt, Wright & Schmall, 1987; Pruchno & Resch, 1989; Sheehan & Nuttall, 1988; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Teresi, Toner, Bennett & Wilder, 1989; Vitaliano, Maiuro, Ochs & Russo, 1989; Wilder, Teresi & Bennet, 1983; Wilder, Teresi & Bennet, 1983a; Worcester & Quayhagen, 1983; Zarit & Zarit, 1982; Zarit, Todd & Zarit, 1986), and the degree of functional disability and difficulty in self-care of the care receiver (Deimling & Bass, 1986; Deimling, Bass, Townsend & Noelker, 1989; Given, King, Collins & Given, 1988; Gonyea, 1987; Hasselkus, 1985; Knopman, Kitto, Deinard & Heiring, 1988; Lund, Pett & Caserta, 1987; Morycz, 1985; Pearson, Verma & Nellett, 1988; Sheehan & Nuttall, 1988; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Vitaliano, Maiuro, Ochs & Russo, 1989; Worcester & Quayhagen, 1983).

In identifying the most difficult aspects of caregiving a limitation of the research to date is that the literature is almost entirely concerned with populations where all or some of the care receivers are cognitively

impaired. Many of these studies have reported relationships between symptoms of cognitive impairment and the outcome of increased caregiver stress and burden. The presence of this variable has made isolating the effect of other variables on caregiving outcomes difficult. Studies that examined the impact of cognitive versus physical impairments of care receivers on caregiving outcomes have reported a significant difference between the groups (Bass, Tausig & Noelker, 1988-89; Birkel, 1987; Poulshock & Deimling, 1984).

The subjective component of the stressor is the extent to which caregivers perceive the demands to be disturbing, threatening, overwhelming or manageable. This aspect of the framework is typically measured with some form of behavior problem checklist where caregivers rate how tolerable or upsetting it is for their relative to exhibit the behavior or disability in question (Gatz, Bengtson & Blum, 1990; Pearlin, Turner & Semple, 1989; Zarit, 1989; Zarit, 1992). These ratings reflect individual differences in the meaning of behaviors to caregivers and in the appraisal of threat from care events (Zarit, 1992). In some studies the caregivers subjective appraisal of problems and subjective feeling of self-confidence in managing these problems has been more predictive of caregiving outcomes than the severity of the actual stressors (Haley, Levine, Brown & Bartolucci, 1987; Pearson, Verma & Nellett, 1988; Sheehan & Nuttall, 1988).

Secondary stressors. The second aspect of stressors identified in the literature are the caregiver related variables. These are the changes in the caregiver's life that are a result of their caregiving role (Gatz, Bengtson & Blum, 1990; Pearlin, Turner & Semple, 1989; Zarit, 1989; Zarit, 1992). Research appears to indicate a relationship between changes in the caregiver's life related to their caregiving role and outcomes as measured by perceived caregiver burden and/or a decision to seek institutionalization of the care receiver. Examples of changes in the caregivers life that have found to be related to outcomes include years of caregiving, social participation, lack of free time, and caregiver health problems (Baille, Norbeck & Baines, 1988; George & Gwyther, 1986; Hirschfeld, 1981; Hirschfeld, 1983; Jones & Vetter, 1984; Montgomery, Gonyea & Hooyman, 1985; Morycz, 1985; Teresi, Toner,

Bennett & Wilder, 1988; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989).

Mediators of stressors. Mediators of stressors are those factors that have an effect on the impact of the stressors on individual caregivers. The primary mediators of stressors proposed in the literature have been coping and social support (Pearlin, Semple & Turner, 1989; Pratt, Schmall, Wright & Cleland, 1985; Stephens, Norris, Kinney, Ritchie & Grotz, 1988; Vitaliano, Maiuro, Ochs & Russo, 1989; Zarit, 1992; Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986). Two major categories of coping strategies that have been found effective in managing caregiver stress are problem solving (Haley, Levine, Brown & Bartolucci, 1987; Pearlin, Semple & Turner, 1989; Zarit, Orr & Zarit, 1985), and modifying meaning (Quayhagen & Quayhagen, 1988; Stephens, Norris, Kinney, Ritchie & Grotz, 1988).

The other major mediator of stresses of caregiving is social support. Social support is both the instrumental and emotional assistance received by caregivers from either informal sources, such as friends and family, or formal services. It has proved to be a consistent and powerful mediator of caregiving outcomes as measured by perceived stress and burden. Higher levels of social support and perceived adequacy of support have been associated with lower levels of perceived burden and better morale in caregivers (Caserta, Lund, Wright & Redburn, 1987; Fengler & Goodrich, 1979; George & Gwyther, 1986; Haley, Levin, Brown & Bartolucci, 1987; Morycz, 1985; Robinson, 1989; Scott, Roberto, Hutton, 1986; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Teresi, Toner, Bennett & Wilder, 1989; Vitaliano, Maiuro, Ochs & Russo, 1989; Zarit, Reever & Bach-Peterson, 1980).

Secondary appraisal. Zarit (1992) describes secondary appraisal as reflecting the process by which caregivers evaluate how adequate their resources are for coping with the stressors. It represents a summation of how the caregiver currently feels about the situation. Measures of subjective burden are thought by Zarit (1992) to be representative of secondary appraisal and may be predictive of caregiving outcomes.

A number of instruments have been developed and many researchers have employed these scales to measure subjective burden (Caserta, Lund, Wright & Redburn, 1987; Deimling & Bass, 1986; Lawton, Kleban, Moss,

Rovine & Glicksman, 1989; Lund, Pett & Caserta, 1987; Montgomery, Gonyea & Hooyman, 1985; Scott, Roberto & Hutton, 1986; Teresi, Toner, Bennett & Wilder, 1989; Vitaliano, Maiuro, Ochs, & Russo, 1989; Zarit & Zarit, 1982). These instruments appear to measure something relevant about the phenomena of caregiving that normative measures do not reflect and have been more responsive in predicting caregiving outcomes and measuring change in intervention studies (Gatz, Bengston & Blum, 1990; Montgomery, Gonyea & Hooyman, 1985; Zarit, 1992; Zarit, Todd & Zarit, 1986).

Outcomes. A variety of approaches have been used to measure outcomes or consequences of caregiving. A variety of indicators have been used by researchers to measure outcomes, including emotional distress, physical illness in the caregiver, reduced social participation, altered relationship with the care receiver, and demands on finances. The term burden was initially used in this context as well (Anthony-Bergstone, Zarit & Gatz, 1988; Baille, Norbeck & Baines, 1988; Caserta, Lund, Wright & Redburn, 1987; Colerick & George, 1986; Deimling, Bass, Townsend & Noelker. 1989; Gatz, Bengtson & Blum, 1990; George & Gwyther, 1986; Moritz, Kasl & Berkman, 1989; Scott, Roberto & Hutton, 1986; Snyder & Keefe, 1985). Another outcome used as a measure by some researchers is that a caregiver may opt out of caregiving, either by institutionalizing the care receiver or turning care over to another (Deimling & Poulshock, 1985; Hirschfeld, 1981, Hirschfeld, 1983; Lund, Pett & Caserta; 1987; Morycz, 1985; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Teresei, Toner, Bennett & Wilder, 1989; Zarit, 1990). Although the literature emphasizes negative outcomes, positive outcomes such as a sense of competence, personal satisfaction, or recognition by others, have been noted (Gatz, Bengtson & Blum, 1990; Lawton, Kleban, Moss, Rovine & Glicksman, 1989; Zarit, 1990).

In summary, Zarit's (1992) framework for caregiving indicates that outcomes of caregiving may be measured in a variety of ways in relation to their effect on the caregiver and or care receiver. These outcomes appear to be affected by the variety of stressors resulting from the needs and the condition of the care receiver and/or changes in the caregivers life; the extent to which caregivers preceive the stressors to be

manageable or overwhelming; and the impact that mediators of stress such as coping and social support have on the caregiver.

Caregiving Stress and Incontinence

Researchers have identified a relationship between perception of caregiver burden, and the care receiver's functional abilities (Deimling & Bass, 1986; Deimling, Bass, Townsend & Noelker, 1989; Given, King, Collins & Given, 1988; Gonyea, 1987; Hasselkus, 1985; Knopman, Kitto, Deinard & Heiring, 1988; Lund, Pett & Caserta, 1987; Pearson, Verma & Nellett, 1988; Sheehan & Nuttall, 1988; Worcester & Quayhagen, 1983). Incontinence and toileting activities are one of the measures of functional ability used in research studies to assess the relationship between stressors and caregiving outcomes (Colerick & George, 1986; Fillenbaum, 1988; Hu, 1990; Jones & Vetter, 1984; Lawton & Brody, 1969; O'Donnell, Drachman, Barnes, Peterson, Swearer & Lew, 1992; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Zarit, Orr & Zarit, 1985).

In those studies that have described a relationship between functional ability of the care receiver as a stressor and increased caregiver burden, incontinence and dependence in toileting have been identified as predictive of increased perception of burden by caregivers (Chenoweth & Spencer, 1986; Given, King, Collins & Given, 1988; Gonyea, 1987; Hasselkus, 1989; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989) and institutionalization of care receiver (Chenoweth & Spencer, 1986; Forbes, Jackson & Kraus, 1987; Hu, 1990; Knopman, Kitto, Deinard, & Heiring, 1988; Lund, Pett & Caserta, 1987; O'Donnell, Drachman, Barnes, Peterson, Swearer & Lew, 1992; Smallegan, 1985; Worcester & Quayhagen, 1983; Zarit, Todd & Zarit, 1986). Continence and independence in toileting have been measured as individual items in larger scales used to provide a measure of the care receiver's functional ability.

The only conclusions that can be drawn from these studies is that there appears to be a relationship between incontinence and dependent toileting in the care receiver and increased burden reported by the caregiver. It may be a factor in the caregiver deciding to seek institutionalization of the care receiver. Of note is that not all studies identify incontinence and dependent toileting as significantly related to

caregiver burden. Only one study provides specific information about the incontinence or the caregiver's subjective appraisal of the incontinence. It is therefore difficult to use the information from these studies in making predictions about what degree or type of incontinence will be perceived by caregivers as burdensome, or which caregivers will perceive incontinence as particularly burdensome.

Only Noelker (1987) specifically addressed the relationship between incontinence in the elderly care receiver and the stress effects reported by their family caregivers. In a secondary analysis Noelker (1987) compared groups of caregivers caring for continent elders with those caring for incontinent elders. She reported that those caring for the incontinent had more perceived stress effects and felt more burdened by care tasks. These perceptions of stress and burden increased with the degree of incontinence and if the care receiver had combined urinary and fecal incontinence. Although incontinence was found to be significantly related to an increased perception of stress and burden, only 13% of caregivers whose care receiver experienced urinary incontinence and 27% whose care receiver experienced urinary/fecal incontinence stated that they viewed incontinence as a serious problem. This study more conclusively establishes a relationship between incontinence and an increased perception of burden by the caregiver, and indicates that subjective burden may be related to the degree and/or type of incontinence. It does not explore other objective and subjective indicators of the stressor incontinence which may be of significance, whether mediators have any effect on the perception of burden, and whether caregiving outcomes are affected in those who experience increased burden related to the incontinence.

Summary

Using the framework proposed by Zarit (1992) (Figure 1) it is possible to identify contextual features, objective and subjective indicators of the stressor incontinence, and mediators of the stressor incontinence which may be associated with increased subjective burden in caregivers. Incontinence of the care recipient has been identified as a stressor that is associated with increased subjective burden in caregivers. In a sample of caregivers of incontinent care recipients Zarit's (1992) framework will be used to organize the proposed study (Figure 2). Measures of

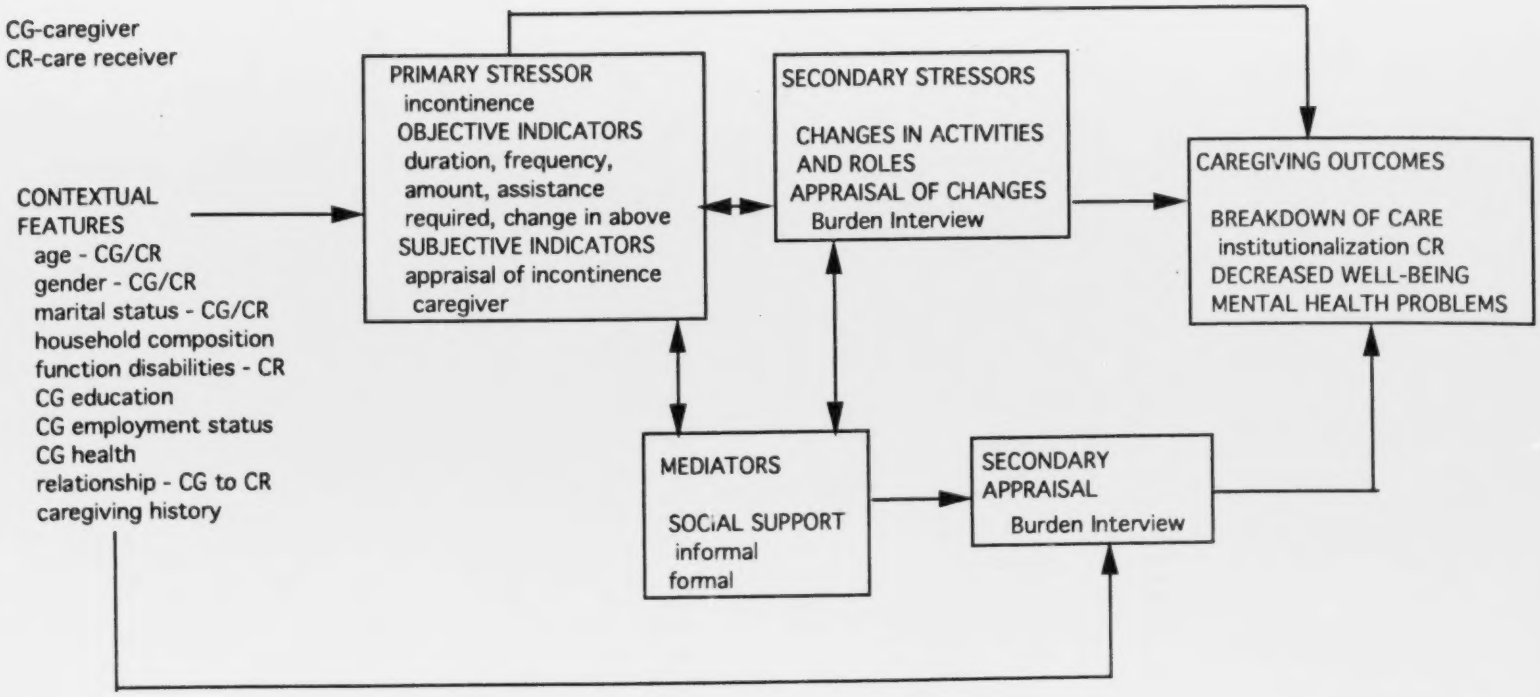

Figure 2
Operational framework

contextual features, objective and subjective indicators of the stressor incontinence, and possible mediators of the stressor incontinence will be analyzed for association with the amount of subjective burden reported by caregivers. In this study relationships between contextual features, objective and subjective attributes of incontinence, and possible mediators of the stressor incontinence were examined for association with the Burden Interview and institutionalization of the care receiver.

Methods

Design

This study used a descriptive design. Although there has been extensive research done in relation to both caregiver burden and incontinence there were aspects of this study which qualified it as descriptive. Athough the literature on caregiver burden has identified incontinence as a stressor that may affect the level of perceived caregiver burden only one has focused on incontinence as a stressor and its relationship to overall caregiver burden. In the case of incontinence, although it appears to be related to increased levels of perceived burden on the part of caregivers only one study (Noelker, 1987) was found which attempted to investigate this specific association. Due to the small sample size, nonrandom nature of the sample, lack of control group for comparison and the addition of information obtained outside of the questionnaire in the interview situation, the information that accrued for the analysis was predominantly descriptive in nature. The study used mixed methods to collect mainly qualitative and some quantitative data. It was cross-sectional, as information was solicited from participants on a single occassion only (Brink & Wood, 1988).

The Sample

A nonprobability convenience sample was studied. Subjects recruited for the study were the caregivers of elderly individuals who were incontinent of urine or required the caregiver's assistance with their toileting to prevent them from being incontinent of urine. The care recipients were 60 years of age or older, resided in a community setting full or part time, or had entered an institution within the 12 months prior to the interview. To be included in the study caregivers identified read and/or understood an English questionnaire, and were willing to participate. The sample consists of 43 caregivers from 4 different sources who met the criteria for selection and consented to participate in the study. Data were collected over a 6 month period with each subject being interviewed on a single occassion.

Procedure

Identification of population. Ethical approval for the study was obtained from the Faculty of Nursing, University of Alberta. Permission to access caregivers was sought at four locations:

1. Edmonton Board of Health
   - Edmonton Home Care Program
   - Edmonton Aids to Daily Living
2. Victorian Order of Nurses
   - Dependent Adult Daycare Program
3. Edmonton General Hospital
   - Incontinence Project
4. The Good Samaritan Society

In each of these instances the researcher met the ethical review requirements of the identified agencies.

Recruitment of sample. A contact person for the researcher was identified at each agency. The contact person introduced clients and caregivers to the research project through a letter (Appendix A) from the researcher which briefly explained the research project and requested the subject's participation by consenting to complete a questionnaire. If they were willing to participate in the study caregivers gave the contact person who had introduced them to the study permission to give the researcher their name and phone number.

Once potential subjects indicated that they were willing to participate in the research project the researcher contacted the subject by phone and arranged to meet both the caregiver and the care recipient at a time and place of their choosing. In this study all 43 of the caregivers interviewed chose to meet with the researcher in their home. The researcher explained the project, answered any questions, and obtained a written consent from both the caregiver and care recipient. The written consent from the caregiver indicated the subjects willingness to participate in the study by completing a questionnaire (Appendix B). The written consent from the care recipient indicated their awareness of the questionnaire being completed by their caregiver (Appendix C). Caregivers were given the option of completing a coded questionnaire independently and returning it to the researcher, or completing it with the researcher verbally. In all instances subjects elected to complete the questionnaire verbally with the researcher.

Methods and Instruments

Data collection. Based on a review of the literature, it was decided to collect data on the contextual features of the caregiving situation,

objective and subjective indicators of the stressor incontinence, mediators of the stressor, and the Burden Interview. Once participants were identified and consented to participate data was collected from two sources: 1) information retrieved by the researcher as direct responses to the questions from the demographic questionnaire and the research questionnaire, and 2) additional information that resulted due to the interview situation and was recorded by the researcher as field notes.

Demographic questionnaire. A data collection instrument was developed by the researcher to retrieve information about care receiver contextual features, the care receiver's functional abilities and the care receiver's cognitive status (Appendix D). These questions were selected from the Alberta Assessment and Placement Instrument (AAPI). The AAPI is a comprehensive assessment tool developed by Alberta Health to coordinate assessment and placement functions for long term care. Its purpose is to assist health care professionals to objectively and comprehensively identify client needs and to determine the most appropriate care and placement options available to meet these needs. It focuses on functional assessment (Alberta Health, 1989; McKenzie, Capuzzi & Will, 1989).

Nurses who have been involved in the development and use of the AAPI have indicated that to date there is only one published source of information concerning the reliability and validity of the instrument (L. Borden & H. Neumann, personal communication, March 20, 1991). The reliability analyses reflect the agreement ratings of pairs of professionals doing assessments and making placement recommendations. In this analysis average agreement for items within assessment domains was acceptable. Kappa aggreement for specific placement levels ranged from 0.67 to 0.76 with an overall Kappa of 0.67. Overall aggreement on the recommended placement was considered good by the authors (McKenzie, Capuzzi & Will, 1989). Initial predictive validity has also been established for the AAPI. Fifty patients were independently assessed at a one month interval resulting in 84% agreement between the two placement recommendations (McKenzie, Capuzzi & Will, 1989).

Care receiver contextual features include the age, sex, marital status, and household composition (items 1-8). Information on care receiver functional abilities includes activities of daily living: mobility;

activities of household management; and an assessment of awareness, orientation, memory, judgement, and decision making ability (items 9-30). In this study all ratings of care receiver functional abilities and cognitive status were the caregivers perception and not the result of assessment of the care receiver by the researcher.

Research questionnaire. Using the framework described by Zarit (1992), the research questionnaire (Appendix E) was developed by the researcher to retrieve information about the following: additional contextual features of the caregiving situation such as the caregiver's age, gender, marital status, and health; indepth information about the stressor incontinence; the caregiver's appraisal of incontinence; the mediators of caregiving stress in relation to incontinence; and the caregiver's preceived burden.

Information about the contextual features of the caregiving situation was operationalized by collecting information about the caregiver's age, gender, marital status, education and employment status, health, household composition, relationship to care receiver, and caregiving history (questions 1-17). These questions come from the OARS Multidimensional Functional Assessment Questionnaire (OMFAQ). This is a valid and reliable questionnaire, developed to provide a multidimensional functional assessment of older adults (Fillenbaum, 1988). The OMFAQ is the result of a procedure that started by selecting standardized items, pretested them for comprehension by the elderly community, rephrased them to improve clarity, and rearranged them to facilitate flow, thus establishing content and consensual validity. Criterion validity, based on the extent to which questionnaire-based assessments agreed with assessments made by professionals following personal interview and agreed with an objective standard, was established using Kendall's tau and Spearman's rank order correlations. There was statistically significant agreement between OMFAQ ratings and the criterion on the relative placement of individuals (Fillenbaum, 1988). Testing for reliability of the OMFAQ focused on test-retest reliability, inter-rater reliability, and intra-rater reliability. In examining test-retest reliability, 90.7% of the responses were found to be identical. Interrater reliability was assessed using the intraclass correlation coefficient derived from an analysis of variance performed for each of the

five OARS scales. The obtained results were statistically significant at an alpha level of .001. In studying intrarater reliability it was found that personal rating style remained highly consistent over a 12-18 month time interval. Pearson product moment correlations between initial and later ratings ranged from .47 to 1.00 with only three of the 35 correlations being significant at less than the $p < .001$ level. One of these was significant at $p < .05$ and the other two at $p < .01$ (Fillenbaum, 1988).

Objective elements of the stressor 'incontinence' (questions 19-30) were operationalized in questions which identified the frequency of incontinent episodes, the degree of assistance required by care receiver, the amount of assistance provided by the caregiver, the duration of incontinence, the change in incontinence over time, the type of incontinence, and whether the incontinence had been investigated medically. Questions were developed by the researcher based on the literature available concerning incontinence, and incontinence and caregivers.

Subjective attributes of the stressor 'incontinence' were operationalized by asking caregivers to respond to questions which asked the caregivers to describe their subjective feelings about caring for their incontinent relative. Several closed and open ended question were developed by the researcher (questions 31-35). These were based on the previous work of Yu (1987) and Noelker (1987). Yu (1987) described the development and pilot testing of a questionnaire directed specifically at the stress that nursing home staff experience in working with incontinent patients. Content analysis of the instrument developed was carried out in three steps: a) frequency distributions of variables, b) Cronbach's alpha was used to examine the internal consistency of the instrument and determined to be 0.84, and c) principal component factor analysis was used to determine the underlying dimensions measured by the instrument. Noelker (1987) used an interview schedule for primary caregivers that included six items designed to ascertain the incidence and frequency of incontinence and how much of a problem the elder's incontinence posed for the primary caregiver. These measures were compared to three measures of caregiver stress effects; Restricted Social Activities, Negative Affect in Family Relationships, and health deterioration in caregiver (Noelker, 1987).

Mediators for caregivers of the stressor incontinence in the care recipient were operationalized by asking caregivers to identify sources of informal and formal support (questions 36-43). The questions used by the researcher are based on those developed by the OMFAQ (Fillenbaum, 1988) and the work by Colerick and George (1986) using the same instrument with caregivers.

In this study subjective burden was operationalized by the Burden Interview (Zarit, Anthony, & Boutselis, 1987; Zarit, Reever & Bach-Peterson, 1980; Zarit & Zarit, 1982) representing a combination of secondary stressors (role strain and conflict) and secondary appraisal (Zarit, 1992) (questions 44-65). The Burden Interview has been specifically designed to reflect the stresses experienced by caregivers and can be completed by caregivers themselves. It is scored by summing the responses of the individual items, with higher scores indicated greater caregiver distress. Zarit and Zarit (personal communication, September, 1990) report that internal reliability for the Burden Interview has been estimated using Chronbach's alpha at .88 (Hassinger, 1985) and .91 (Gallagher, Rappaport, Benedict, Lovett & Silven, 1985). Test-retest reliability is reported at .71 (Gallagher, Rappaport, Benedict, Lovett & Silven, 1985). Validity has been estimated by correlating the total score with a single global rating of burden ($r = .71$), and by correlating the total score with the Brief Symptom Inventory (Derogatis, Lipman, Covl, Richels & Uhlenhuth, 1970) ($r = .41$). The internal reliability of this tool was re-established in this study using Cronbach's alpha.

Validity. The questionnaire is a compilation of questions and items from a variety of sources, only some of which have published data concerning their reliability and validity. To establish face and content validity for the questionnaire in its present form the questionnaire was reviewed by a panel of three expert nurses: 1) a nurse working in the field of geriatric incontinence, 2) a nurse who is familiar with the development and use of the AAPI, and 3) a nurse who is working in the community with elderly caregivers and care recipients. Suggestions put forth by the nurses who reviewed the questionnaire were incorporated in the document.

Following the review of the questionnaire for face and content validity and the incorporation of revisions, it was pilot tested. Three (3)

caregivers who met the criteria outlined in the sample selection were solicited to complete the questionnaire. They were asked to keep a record of the time required to complete it and any difficulties or questions they encountered. There were no significant revisions to the questionnaire as a result of this process.

Field notes. All the caregivers participating in the study chose to complete the questionnaire in an interview situation. This resulted in the researcher becoming aware of a great deal of information that had an impact on the results of the research yet was not reflected in the quantitative data provided by the questionnaires. This information was volunteered by both the caregivers and those care receivers who were present during the interview. These additional data were recorded by the researcher as field notes immediately following each interview.

Data Analysis

Data collected from the questionnaires completed by the participating caregivers were of a nominal and ordinal nature. Due to the size and nature of the sample and the type of data obtained the analysis of the information consisted of descriptive statistics and measures of association. Due to the descriptive and exploratory nature of this research, inferences from this sample to other samples of individuals will not be possible.

Data collected were initially summarized in terms of frequencies and distribution among the various categories or over the various possible values. Central tendencies are discussed in terms of modal and median values. Measures of variation in the variables are presented in terms of range and percentiles.

For the quantitative data obtained an analysis of possible associations between each of the independent variables and the Burden Interview was attempted using Pearson correlation coefficient.

Information obtained from the open ended questions and documented in field notes was used to further describe the variables and provide additional information related to the quantitative results from the questionnaire.

The internal reliability of the burden interview within the questionnaire was determined using the tests described by Zarit & Zarit (1983). Data analysis measured the degree of association between the

caregiver's perceived burden and the other identified variables. Due to sample size and nature of the data, no further analyses were undertaken.

Ethical Considerations

Subjects consenting to participate in the research study did so voluntarily by giving the person who introduced them to the study permission to give the researcher their name and phone number and by signing informed consent. Potential subjects were initially provided with a letter briefly describing the research project. The letter assured all potential subjects that their participation was voluntary and would not affect any service they were receiving in relation to their incontinence in any way. Those who responded positively to this initial request were personally contacted by the researcher.

Prior to participating in the research project, both caregiver subjects and their care recipients signed an informed consent. This consent explained the research project to them; affirmed that their participation was voluntary, anonymous, and confidential; and addressed the method by which they could withdraw from the project. At this time subjects could address any questions they had concerning the research project directly to the researcher. The consent letter also provided the subjects with contact persons should they have questions or concerns after the researcher left.

Subjects were assured of confidentiality. In all the questionnaires and the researcher's field notes the subjects were identified by number only. There was only one copy of the list of names and addresses and their corresponding number code. This was retained by the researcher for the duration of the data collection phase of project. The list was kept in a locked drawer separate from the collected data and completed questionnaires. At the end of the data collection phase the list of subject names and their assigned code numbers was destroyed. No one need know the individuals who have participated in the study unless they themselves share this information.

Subjects were assured of anonymity. Data collected, questionnaires returned to the researcher, and all field notes were identified only by a number code. Once the data collection was complete, and the list of subject names destroyed, it was impossible to associate data with individual respondents. When the data is presented, individuals will not

be identified. Statistical analysis was done in terms of groups not individuals. The data itself will be retained for a minimum of 7 years for educational and research purposes.

Limitations

1. Incontinence is a sufficiently discrete variable to be addressed apart from other variables that affect burden. Two potential confounding variables that have been identified in the literature are cognitive impairment of the care receiver and additional functional impairments of the care receiver, both of which may affect the caregiver's subjective burden. Data were collected on the functional and cognitive disabilities of the care receiver in areas others than elimination. The effect of these potentially confounding variables on the caregiver's perceived burden was then examined.

2. Caregivers will report accurately when completing the questionnaire. A consideration in all studies that require participation, accurate reporting is of particular concern in this instance where the subject matter concerns such an intimate and private topic. The researcher attempts to control this factor by using a volunteer sample, thus ensuring that they wish to participate in the study. Further, all participants were assured of confidentiality in the collection of data and anonymity in data analysis and reporting.

3. Identification of participants in the study by self-selection. The sample that is accessed by the researcher may be biased by the contact persons not identifying or presenting the opportunity to participate in the study to caregivers and care receivers who may have met the criteria. The opportunity for subjects identified to choose whether they wish to participate in the study or not provides yet another point for self-selection to bias the sample and therefore the findings.

Findings

In this study a total of 54 questionnaires were completed by caregivers of incontinent care receivers. In this sample 43 met the criteria for inclusion in the analysis. Reasons for exclusion were age of care receiver, care receiver living in institution fulltime for more than 1 year, care receiver does not require assistance to manage incontinence, and caregiver is a paid aide.

The original proposal as approved called for the completion of 100 questionnaires. Data collection was stopped at 54 following the exhaustion of available participants at the four sites accessed: Edmonton Home Care, The Good Samaritan Society, Victorian Order of Nurses Dependent Adult Day Care Program, and the Edmonton General Hospital Incontinence Project. At this point data collection had been ongoing for 6 months, with 100% of the caregivers opting to complete the questionnaire in an interview format with the researcher. In making the decision to terminate data collection, expand the search for caregivers to additional sites, or extend the time frame for collection further, the data collected to this point was reviewed. The caregivers interviewed to that point represented a number of caregiving situations with the majority of the caregivers in each of these situations indicating that incontinence was something they were willing to manage. It was thought that extension or continuation of the collection within the identified parameters would not identify caregivers in different situations or large numbers of caregivers who were unwilling to manage incontinence.

Description of the Care Receivers

The care receivers included in the study meet the criteria as outlined in sample selection. They are over the age of sixty and are incontinent of urine and require the assistance of a caregiver to manage their incontinence and toileting. There were 43 distinct caregiver interviews suitable for inclusion in the study, caring for a total of 41 different care recipients. In two instances both the daughter and the spouse of the care recipient were interviewed as they both cared for the care recipient, assisting them with their toileting and/or incontinence.

Care receiver and caregiver demographics. Care receiver and caregiver demographics are summarized in Table 1. Care receivers range in age from 63 - 92 years with a mean of 77 and a mode of 75-80. In the

Table 1
Demographics: Care Receiver and Caregiver

	Care receiver		Caregiver	
	n	%	n	%
Age				
<60 years	0	0	15	35
60 - 70 years	8	18	7	16
70 - 80 years	17	40	15	35
>80 years	18	42	6	14
Sex				
Male	23	53	12	28
Female	20	47	31	72
Marital Status				
Single	1	2	4	9
Married	35	82	37	87
Separated/divorced	0	0	1	2
Widowed	7	16	1	2
Relationship of Caregiver to Care Receiver				
Spouse			32	74
Child			8	19
In-law			2	5
Other relative			1	2
Caregiver Residence				
Fulltime with care receiver			31	72
Part-time with care receiver			6	14
Separate			6	14

sample group their were 23(53%) male care recipients and 20(47%) female care recipients. In this group of care receivers 1(2%) was single with a relative providing care; 35(81%) were married with 32(91%) of these receiving care from their spouse and 3(9%) from children or children and spouse; and 7(16%) were widowed and receiving care from a child or in-law. Care receivers living in a home, either singe or multi-family,

accounted for 33(77%) of the sample. The remaining 10(23%) now called a nursing home or auxiliary hospital their primary residence. Those who were living in a nursing home or auxiliary hospital had been incontinent at home prior to their admission, had required assistance with their toileting and/or incontinence, and had been in the institution less then one year. Of the 10 care recipients living in an institution 6 are coming home to their caregiver on a regular basis, usually for weekends and longer periods of time over holidays.

Care receiver physical and self-care abilities. Caregivers were asked in the questionniare to provide their assessment of the care receiver's physical and self-care abilities by rating the amount of assistance that was required or provided to the care receiver (Table 2). In this sample 75% of the care recipients were able to feed themselves with minimal assistance from their caregiver. For the other self care activities rated (dressing, grooming, bathing, and toileting) a minimum of 75% of care receivers required caregiver supervision and physical assistance to complete the task. Approximately 50% of the care receivers could mobilize independently indoors and transfer themselves with and/or without the use of mobility aids. More then 80% of the care receivers required the direct assistance of their caregiver to mobilize on stairs and outside. All of the care receivers were dependent for transport. In more then 90% of the interviews the caregiver reported doing all of the shopping, banking, meal preparation and housecleaning for the care receiver. As a group the care receivers were severely compromised in their physical and self care abilities. Without the assistance of their caregiver to assist with and complete activities of daily living all would require the services of a paid caregiver, either in their home or an institutional setting. The caregivers interviewed spoke of making arrangements for the care receiver's needs when they needed to be away for varying periods of time. The arrangements included: another relative or friend staying with the care receiver, the provision of a personal care aide in their home on a regular part-time basis, transportation of the care receiver to a dependent adult day care program on a regular basis, and admission of the care receiver into a respite space at a nursing home or auxiliary hospital level of care. Not a single caregiver who was interviewed felt

comfortable leaving the care receiver alone for any longer then 2-3 hours at a time.

Table 2
Care Receiver Physical and Self-Care Ability in Percentages (n=43)

	Level1 %	Level2 %	Level3 %	Level4 %	Level5 %
Eating	37	16	19	21	7
Dressing	15	0	5	40	40
Grooming	23	2	14	28	33
Bathing	2	2	2	21	73
Toileting	19	2	2	16	61
Mobility					
Inside	16	30	0	21	33
Outside	7	14	0	16	63
Stairs	5	5	0	25	65
Transport	0	2	0	0	98
Banking	0	2	2	5	91
Meal Preparation	0	2	0	2	96
Housecleaning	0	2	0	2	96

Note. Description of levels are as follow. Level 1 - independent; Level 2 - independent with aids or tools; Level 3 - independent with assistance to set up; Level 4 - requires continuous supervision and/or assistance; Level 5 - requires caregiver to physically assist or perform the task.

Care receiver cognitive ability. Caregivers were also asked to give their assessment of the care receiver's cognitive ability in terms of awareness, orientation, memory, and judgement/decision making ability. Caregivers stated that 22(50%) of care receiver were responsive in terms of awareness, and oriented to person, place, and time; 13(30%) stated that care receiver memory and decision making ability was unimpaired. The degree of cognitive impairment perceived by the caregivers in the remaining care receivers varied with each of the variables assessed.

Caregivers stated that 19(44%) of care receivers had reduced or fluctuating awareness. Only one (1) caregiver rated the care receiver as unreponsive. Caregivers rated 20(47%) of the care receivers as disoriented to time and/or place. Only two (2) caregivers rated the care receiver as disoriented to person. Caregivers stated that 27(63%) of the care receivers had significant memory impairment especially to immediate and recent events. and 30(70%) stated that the care receiver had impaired judgement and decision making abilities. Overall the caregivers felt the care receiver were oriented and responsive to them most of the time but were dependent on the caregivers because of their impaired memory, judgement, and decision making abilities.

Caregiver supervision of care receiver. Each of the care receivers represented in the study required the supervision or assistance of the caregiver to manage activities of daily living and mobilization. The majority of caregivers felt they could not leave the care receiver unattended. Those caregivers who left the care receiver unattended were only comfortable doing so for 1-3 hours. All caregivers expressed a concern for the physical safety of the care receiver if unattended. For over 90% of the caregivers in the study the only period of time they were not responsible for the care receiver was if a family member or paid aide came to stay with the care receiver while they went out; or the care receiver was attending an adult day care program on a regular basis.

Care receiver incontinence. All care receivers were incontinent of urine and/or required assistance with their toileting without which they would be incontinent. Care receivers had been incontinent for 1 month to 16 years with both the mean and mode for the group being 3-3.5 years. The care receivers had required assistance to manage their incontinence and/or toileting from 1 month to 9 years with the mean being 2.5 years. Many of the care receivers had been incontinent and independent in managing their incontinence for varying periods of time before they required assistance from the caregiver to manage their incontinence.

In this sample 37(85%) of care receivers were incontinent daily or more then once daily, either dribbling urine continuously or emptying the bladder completly with each incontinent episode, with 43(100%) requiring supervision and assistance from the caregiver to manage their toileting. Without the assistance of the caregiver to manage toileting

100% of the care recievers would experience incontinent episodes on a daily basis. In the majority of care receivers the frequency and volume of incontinence experienced had not changed or had increased during the past year. Caregivers reported that 26(60%) of the care receivers had required more assistance in the past 6 months and 1 year in managing their toileting and/or incontinence. The overall picture presented by the group of care receivers is one of frequent incontinence of urine, in amounts sufficient to require protective clothing, and requiring the assistance of a caregiver to manage without which assistance the care receiver would be incontinent. All three of the variables (frequency, volume of urine, and assistance required) had remained constant or increased in severity with time.

Caregivers stated that 31(75%) of the care receivers required assistance to manage their incontinence at night with 15(35%) requiring this assistance more then once per night. Assistance described by caregivers included physical help to the bathroom, assistance with bedpans or urinals, changing of protective clothing, changing of nightwear and bedding, and getting up during the night to catheterize the care receiver.

In this sample 30(70%) of the care receivers had had their incontinence investigated by a physician. In two of these cases the investigation resulted in treatment of the condition causing the incontinence and a subsequent end to the incontinence. Others experienced temporary or permanent improvement of symptoms. While the investigation did not change the incontinence in many instances, it increased care receiver and caregiver knowledge and control of the situation resulting in a positive outcome for all involved.

Description of the Caregivers

There were 43 caregivers who met the criteria for the study and agreed to complete the questionnaire. They were given the option of completing the questionnaire with the researcher or completing it after the researcher left and returning it by mail. All 43 elected to complete the questionnaire with the researcher in a interview situation with all interviews conducted in the home of the caregiver. Additional information from these interviews was recorded in the form of field notes written by the researcher following each interview.

Caregiver demographics. Some of the caregivers demographics are summarized in Table 1. The caregivers ranged in age from 38 years to 83 years with a mean of 66 years and a mode of 75-80 years. In this sample 26(60%) of the caregivers were 65 years of age or older. Of the caregivers interviewed 12(28%) were male and 31(72%) were female. Four(9%) of the caregivers were single and all of these individuals were daughters of the care receiver. One of the caregivers was separated/divorced, a daughter of the care receiver, and one was widowed, also a daughter of the care receiver. The remaining 37(87%) caregivers were married. Of these 37, 32(86%) were the spouses of the care receiver. The 5 married caregivers who were not spouses of the care receiver were daughters (2), in-laws (2), and other relatives (1). In the group of male caregivers interviewed only one was not the spouse of the care receiver. He was a son-in-law. Therefore, 11 of the spousal caregivers were male and 21 were female. Of the 26 caregivers interviewed who were over the age of 65 years 25 of them were spouses of the care receiver.

Caregiver/care receiver living arrangements. In this group of caregivers 31(72%) lived in single family residences, 11(20%) in multifamily residences, and 1(2%) in a lodge. Spousal and nonspousal relationships were represented in all types of dwellings as were situations where the care receiver lived with the caregiver fulltime, part-time, or not at all. In this sample 41(95%) of those caregivers interviewed lived within the greater Edmonton metropolitan area making the sample predominantly urban.

Living arrangements of the caregiver and care receivers are summarized in Table 3. Of those who did not currently live with the care receiver, 2 were daughters of the care receiver who maintained their own residence in addition to assisting the care receiver on a daily basis. The remaining 4 were spouses of a care receiver who had entered a nursing home/auxiliary care facility in the past year and did not come home on a regular basis. The caregivers who lived with the care receiver part-time brought a care receiver who was living in a nursing home/auxiliary facility home on a regular basis. These care receivers usually spent 2-3 days per week living in the home of the caregiver. Of the 31 caregivers who had the care receiver living with them fulltime, 25(81%) were spouses of the care receiver, 5(16%) were children or in-laws of the care

receiver and 1(3%) was a niece of the care receiver. All 6 nonspousal caregivers had moved the care receiver into their home to care for them as the care receivers in these instances were unable to continue living independently without assistance. One was awaiting placement of the care receiver and the remaining 5 caregivers had no plans to change this living arrangement.

Table 3
Living Arrangements: Caregiver and Care Receiver

	Fulltime		Part-time		Separate	
	n	%	n	%	n	%
Total	31	72	6	14	6	14
Spouses	25		3		4	
Children	5		3		2	
Other relative	1		0		0	

The number of individuals living fulltime in the residence of the caregiver ranged from 1-8. In the 8 instances where only 1 person lived in the home the care receiver was not living in the same residence as the caregiver on a fulltime basis. In the 11 instances where more then 2 individuals lived in the home, 5 were spousal relationships where another relative was living in the home, and 6 were situations where the care receiver had moved into the home of a child, in-law, or other relative where there were additional family members. In 22 of the 24 instances where 2 persons lived fulltime in the caregiver's residence the relationship was spousal and in the other 2 a parent care receiver was living with a child who was caregiver.

Caregiver education. In the sample of caregivers interviewed 9(21%) had not graduated from high school, 15(35%) had completed high school, and 19(44%) had completed some type of post secondary education.

Caregiver employment status. In the caregiver group 35(81%) of the classified themselves as retired or homemakers. The 4 who called themselves homemakers were spouses to care receivers and had never worked outside the home. Although they were over 65 years old, because they continued to work at home they called themselves homemakers. Caregivers worked fulltime or part-time outside of their home accounted for 7(16%) of the sample. Of these, only 2 had the care receiver living with them on a full-time basis. One caregiver described himself as unemployed. He had been laid off work 1 month before his wife suffered a massive stroke, 5 years previously, and now cared for her fulltime so was unable to seek employment.

Caregiving history. Caregivers had been providing care to the care receiver from 2 months to 12 years with a mean of 61 months, just over 5 years. Only 3 caregivers had provided care for less then 1 year. In this sample 29(67%) of the caregivers provided care to the care receiver 24 hours per day, 7 days per week. Those not in this category included cases where the care receiver was now living in a nursing home/auxiliary facility during the week and home on the weekend. When they had the care receiver at home these caregivers were providing care 24 hours per day. Other caregivers who did not provide care 24 hours per day 7 days per week were in situations where the care receiver attended a dependent adult day care program. This usually took the care receiver out of the home for 4-6 hour period, 2-3 days per week. During this time the caregiver did not have direct caregiving responsibilities.

Although variable depending on the disability of the care receiver, in addition to assisting the care receiver in relation to their incontinence and/or toileting most caregivers were providing some assistance to the care receiver with dressing, grooming and mobility. Almost all caregivers were totally responsible for shopping, banking, meal preparation, housecleaning, and laundry, receiving no assistance from the care receiver due to their reduced physical and self-care abilities.

Caregiver health. In reporting on their own health 28(65%) of the group of caregivers had seen a physician less then 2 times in the

preceding 6 month period and the mean for the entire group was 2.5 visits in the preceding 6 months. Only 2(5%) of the caregiver group had been hospitalized in the preceding 6 month period, and only 3(7%) stated that they had any days during the previous 6 months when they were too ill to give care to the care receiver. In rating their own health 32(73%) of the caregivers rated it as good or excellent with 33(75%) stating that their health was the same or better then one year ago. Given the overall age of this group of caregivers, mean of 66 years with 60% of them being over 65 years of age, the level of health as reported is extraordinary (Crichton & Hsu, 1990). Of interest is the fact that fully 100% of the caregivers expressed awareness of how their own health impacted on their ability to meet the needs of the care receiver. Many of them voiced concerns over what would happen if they were ill and unable to provide the necessary care and assistance that the care receiver required. Most of them saw their own health as the most important factor in their ability to continue providing care for the care receiver. The most common statement concerning their decision to continue caring for the care receiver was to the effect that they had every intention of doing so as long as their own health held up. In the case of those caregivers who had placed the care receiver in a nursing home/auxiliary facility in the past year, the most common reason for doing so had to do with their own declining health and subsequent inability to provide the necessary care.

Informal support to caregiver. Only 8(19%) of the caregivers interviewed received help from other family members on a regular basis in caring for the care receivers' incontinence. The rest reported that they received assistance only occasionally (12%), if requested (14%), rarely (21%) and never (35%). When asked if they desired more assistance in caring for the care receiver's incontinence 30(70%) stated no while 12(27%) replied sometimes or yes. Of the 70% who replied no, they frequently qualified the response with a statement that this was their responsibility, that they didn't expect other family members to do this, or they felt that such assistance from persons other than themselves would embarass the care receiver. Of those caregivers who replied sometimes or yes most stated that they desired assistance and support from family members for any number of things and were not referring specifically to

the desiring of assistance in relation to the care receiver's incontinence. Most wished the family would assist more by supervising the care receiver so they could go out, with part of this supervision being in relation to the care receiver's incontinence.

Formal support to caregiver. The caregivers interviewed accessed a variety of available services to assist them in meeting the needs of the care receiver. In this group 34(79%) of the caregivers received financial assistance in buying incontinence supplies. Those caregivers who had been assisting the care receiver for over 2 years mentioned the changes in funding regulations governing this financial support. Those who were on limited fixed incomes indicated that the changes have been difficult to accomodate. The provision of regular weekly or biweekly bath assistance for the care receiver was the other most commonly accessed service used by this group of caregivers. Homecare provided this assitance to 22(51%) of the care receivers. In most of the cases where the bath assistance was provided the caregiver was unable to physically provide this assistance to the care receiver. The caregivers managed the hygiene needs of the care receiver between baths with sponging. In addition to bath assitance 15(35%) of the care receivers also had regular aide assistance for activities other then bathing. In some instances this was provided by home care and in others the caregiver was arranging and funding this assistance personally. Laundry assistance was provided for 5(11%) of the caregivers interviewed. This was provided by homemakers who helped with housecleaning.

Caregiver appraisal of incontinence. In discussing the care receivers' incontinence 20(47%) of the caregivers stated that the incontinence of the care receiver was no problem for them while 17(40%) stated it was somewhat of a problem and 6(13%) stated it was a great problem. Most of those who stated it was a problem defined the problem in terms of extra work and inconvenience. When asked if the fact that the care receiver was incontinent had changed their feelings about them 40(93%) of caregivers responded with an unequivocal 'no'. Of the 3(7%) who answered that their feelings had changed they qualified their statement. Caregiver statements include: "What can you do about sickness?"; "It's hard to deal with my husband but the incontinence hasn't changed my feelings."; "Somehow or other the respect for a partner diminishes as

each little thing gets taken away, but I still love him."; "Our relationship has become more platonic."; "I'm more protective of him the past few years."; and "He's still my sweetheart".

Caregivers were further asked if because of the care receivers' incontinence they ever felt unable to care for them any longer. In this case 38 (88%) of the caregivers stated that the incontinence was never a reason for feeling unable to care for the care receiver any longer. There were no caregivers who stated that they frequently or nearly always considered the care receivers incontinence a reason for being unable to care for them any longer. When asked this question many expanded on their response. It was in this expanded response that caregivers described the maintenance of their own health and their ability to provide for the needs of the care receiver as being critical elements in their continued caregiving.

Caregiver Response to Burden Interview

Each of the caregivers interviewed completed the Burden Interview (Zarit & Zarit, 1983). The caregiver responses were analyzed as described by Zarit and Zarit (1983) (Table 4).

Zarit and Zarit(1983) measured internal reliability for the Burden Interview using Chronbach's alpha. This measure of reliability was applied to the results obtained on the 22 item Burden Interview. An alpha of .85 was obtained, comparing favorably to the results reported by Zarit (1988). Zarit reports an alpha of .88 (Hassinger, 1985) and .91 (Gallagher, Rappaport, Benedict, Lovett & Silven, 1985). In this population of 43 caregivers, the results obtained by the researcher can be used as a reliable measure of burden as defined by Zarit and Zarit (1983).

Validity has been estimated by correlating the total score with a single global rating of burden, the last question in the Burden Interview (r = .71) (Zarit & Zarit, 1983). In this study the same test of validity was applied to the results obtained on the 22 item Burden Interview (r = .61). In this population of 43 caregivers, the results obtained by the researcher can be used as a valid measure of burden as defined by Zarit and Zarit (1983).

Table 4

Caregiver Response to Burden Interview in Percentages (n=43)

	Never %	Rarely %	Smtms %	Qt Frqt %	Nrl Lws %
Do you feel that your relative asks for more help than he/she needs?	51	7	26	7	9
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	26	7	39	7	21
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	23	12	33	9	23
Do you feel embarrassed over your relative's behavior?	72	12	9	2	5
Do you feel angry when you are around your relative?	33	12	53	0	2
Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	70	7	7	9	7
Are you afraid of what the future holds for your relative?	33	9	37	14	7
Do you feel your relative is dependent upon you?	0	2	1	0	96
Do you feel strained when you are around your relative?	58	12	19	7	4

Caregiver Response to Burden Interview

	Never %	Rarely %	Smtms %	Qt Frqt %	Nrl Lws %
Do you feel your health has suffered because of your involvement with your relative?	49	14	14	9	14
Do you feel that you don't have as much privacy as you would like because of your relative?	70	5	14	2	9
Do you feel that your social life has suffered because you are caring for your relative?	21	21	18	12	28
Do you feel uncomfortable having friends over because of your relative?	81	0	5	7	7
Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	32	5	7	12	44
Do you feel that you don't have enough money to care for your relative in addition to the rest of your expenses?	66	7	16	2	9
Do you feel that you will be unable to take care of your relative much longer?	49	16	14	14	7
Do you feel that you have lost control of your life since your relative's illness?	63	2	19	7	9

Caregiver Response to Burden Interview

	Never %	Rarely %	Smtms %	Qt Frqt %	Nrl Lws %
Do you wish you could just leave the care of your relative to someone else?	67	14	14	5	0
Do you feel uncertain about what to do about your relative?	56	7	26	9	2
Do you feel you should be doing more for your relative?	70	14	12	2	2
Do you feel you could do a better job in caring fo your relative?	65	16	12	7	0

Note. Smtms = sometimes; Qt Frqt = quite frequently; Nrl Lws = nearly always.

In response to the global question on caregiver burden, overall how burdened do you feel in caring for your relative (22), this group of caregivers did not identify themselves as burdened. Of the caregivers interviewed 33(77%) stated that they never, rarely, or only sometimes felt burdened in caring for the care receiver. Caregivers frequently commented on and clarified their feeling in relation to this statement: "I don't have to do this, I want to", "I do it with pleasure", "It's no burden at present but anticipate at some point we won't be able to handle her", "It's my life to look after him, my choice...would like better but don't think it will happen", "It is a burden I can carry and will carry...doesn't make me bitter", "It's part of my life to look after her", "Something I wanted to do...wish I could have kept her till end...worried about running away", "It's hard but I want to do it", "My wife has never been a burden to me", "I view it as a responsibility or job...not a burden", "It's not a burden...it's something you do...it's life", "He's my husband...could be me

and him doing the looking after". The remaining 10(23%) of caregivers stated that they frequently, or nearly always felt burdened in caring for the care receiver. They also frequently qualified their feeling of burden: "When caring for three (children of the caregiver) I do feel this way", "At the end I just couldn't do it anymore", "She is a burden but it's a burden I accept".

The correlation of the total score with the singe global rating of burden (r=.61) indicated a relationship between those caregivers who state they feel burdened and who scored higher on the burden interview. Zarit and Zarit (1983) indicated that norms for the Burden Interview have not been computed but estimates of the degree of burden have been made from findings. These estimates are: 0 -20 little or no burden, 21 - 40 mild to moderate burden, 41 - 60 moderate to severe burden, and 61 - 88 severe burden. In this group of caregivers, 19(44%) scored between 41 and 60 indicating moderate to severe burden, and 9(21%) scored between 61 and 88 indicating severe burden. Those who are reporting that they feel burdened by their caregiving responsibilities have summed burden scores indicating higher levels of perceived burden ($r = .61$, $p < .001$). Caregivers who reported feeling more burdened when asked the global question on perceived burden had higher summed scores on the othe 21 items in the Burden Interview.

Relationship of Burden Interview to Identified Variables

As instructed by Zarit and Zarit (1983), items in the questionnaire were compared to a summed score of the individual items in the Burden Interview using Pearson correlation coefficient (Tables 5 - 10).

Relationship between burden and contextual features. The first research question ask if there is a statistically significant relationship between the subjective burden reported by primary caregivers of incontinent dependent elderly and specified contextual features. The contextual features the literature identified as important, and the researcher collected data on, are caregiver age, care receiver age, caregiver gender, care receiver gender, caregiver marital status, care receiver marital status, caregiver's relationship to the care receiver, household composition, type of residence, caregiver education, caregiver employment status, duration of caregiving, hours of caregiving required per day, changes in hours of caregiving required per day, caregiver health, and

changes in caregiver health. Using Pearson correlation analysis only caregiver health ($r = .41$, $p < .01$) was significantly associated with burden (Table 5). This item asked the caregiver to rate their own health as excellent, good, fair, or poor. Those caregivers who rated their own health as fair or poor were reporting heigher levels of perceived burden then were caregivers who rated their own health as excellent or good.

Table 5
Correlation Between Burden Interview Summed Score and Specified Contextual Features (n=43)

	Correlation	R-squared
Care receiver age	-.282	.08
Caregiver age	-.144	.021
Care receiver gender	-.091	.008
Caregiver gender	-.062	.004
Care receiver marital status	-.006	.00003
Caregiver marital status	.03	.001
Caregiver/care receiver residence	.382	.146
Caregiver/care receiver relationship	-.094	.009
Caregiver education	-.163	.027
Caregiver employment status	-.161	.026
Duration of caregiving	.26	.068
Hours/day of caregiving	.032	.001
Caregiver health	.412**	.17
Recent change in caregiver health	.091	.008

** significant at .01

Relationship between burden and objective stressors. The second research question asks if there is a statistically significant relationship between the subjective burden reported by primary caregivers of incontinent dependent elderly and the stressors that are present in the caregiving role. Those stressors identified as possibly confounding the results of the study were cognitive impairment in the care receiver and

Table 6
Correlation Between Burden Interview Summed Score and Caregiving Stressors (n=43)

	Correlation	R-squared
Care receiver functional abilities		
Eating	-.049	.002
Dressing	.3	.09
Grooming	.014	.0002
Bathing	.162	.026
Toileting	.222	.049
Care receiver mobility		
Indoors	.097	.01
Outdoors	-.004	.00001
Stairs	.083	.007
Transfer	.134	.018
Transport	.107	.011
Care receiver activities of daily living		
Shopping	.229	.053
Banking	.227	.052
Meal preparation	.229	.053
Housecleaning	.229	.053
Care receiver cognitive status		
Awareness	.23	.053
Orientation	.223	.053
Memory	.141	.02
Judgement	.309	.096

Note: no significant findings

the degree of functional disability and difficulty in self care of the care receiver. Using Pearson correlation there was no significant association between burden and the degree of cognitive impairment as reported by the caregiver, the degree of functional disability and difficulty in self care

of the care receiver as reported by the caregiver, or a summed measure of these variables (Table 6).

The second research question addresses whether there is a statistically significant relationship between the subjective burden reported by primary caregivers of incontinent dependent elderly and the objective indicators of the stressor 'incontinence'. Information was solicited from the caregivers concerning the objective elements of the care receivers incontinence which may have some effect on the caregivers perceptions of burden. These were duration of care receiver incontinence in months, number of months care receiver has required assistance to manage incontinence/toileting, frequency of incontinence, change of frequency over time, amount of urine in each incontinent episode, change in amount over time, amount of assistance provided by caregiver in management of care receiver incontinence, change in amount of assistance over time, how often care receiver required assistance with incontinence/toileting at night, and whether incontinence had been investigated by a physician. Using Pearson correlation there was no

Table 7

Correlation Between Burden Interview Summed Score and Stressor Incontinence (n=43)

	Correlation	R-squared
Duration CR incontinence	-.117	.014
Duration of CG assistance with incontinence	-.118	.014
Amount of assistance provided by CG	.174	.03
Change in assistance provided by CG (1 yr)	.219	.048
Frequency of CR incontinence	.11	.012
Change in frequency of CR incontinence (1 yr)	.219	.048
Amount of CR incontinence	-.094	.009
Change in amount of CR incontinence (1 yr)	.13	.017
Frequency of nocturnal incontinence	.059	.003
CR incontinence investigated by physician	-.028	.001

Note. CR = care receiver; CG = caregiver; no significant findings

significant association between burden and any of the objective indicators of the care receiver's incontinence as reported by the caregiver (Table 7).

Relationship between burden and subjective indicators of stress. The second research question also asks if there is a statistically significant relationship between the subjective burden reported by primary caregivers of incontinent dependent elderly and subjective indicators of the stressor 'incontinence'. Appraisal of the subjective indicators was solicited by asking caregivers to respond to questions which described their feelings about caring for their incontinent relative. Caregivers were asked how much of a problem the care receiver's incontinence was, if their feelings toward the care receiver had changed because of the incontinence, and whether the incontinence affected their decision to continue caring for the care receiver. Using Pearson correlation two of these questions demonstrated significance with burden (Table 8). Those caregivers who reported higher levels of perceived burden were more likely to have indicated that their feelings toward the care receiver have changed as a result of the care receiver's incontinence

Table 8
Correlation Between Burden Interview Summed Score and Caregiver Appraisal of Stressor Incontinence(n=43)

	Correlation	R-squared
CG's current feeling about the CR incontinence (problem)	.277	.077
Change in CG feeling towards CR as a result of incontinence.	-.517**	.267
Does CG feel unable to care for CR any longer because of incontinence	.422*	.178

Note. CG = caregiver; CR = care receiver; * significant at .01; ** significant at .001.

($r = -.52$, $p < .001$). There was a positive correlation ($r = .42$, $p < .01$) between those caregivers who stated they were unable to continue caring for the care receiver any longer because of their incontinence and higher levels of perceived burden. Those caregivers who reported higher levels of perceived burden indicated that the care receiver's incontinence may affect their ability to continue providing care.

Relationship between burden and mediators of stress. The third research question asks if there is a statistically significant relationship between the subjective burden reported by primary caregivers of incontinent dependent elderly and informal social support as a mediator of the stressor 'incontinence'. Caregivers were asked whether they received assistance from family and/or friends in looking after the care receiver, if family members were aware of the care receiver's incontinence, and whether they wanted more help or assistance from family. Using Pearson correlation there was no significant association between burden and caregiver response to these questions (Table 9).

Table 9
Correlation Between Burden Interview Summed Score and Informal Support(n=43)

	Correlation	R-squared
Amount of help CG receives from family members	-.203	.041
CG desire for more assistance from family members	-.213	.045

Note. CG = caregiver; no significant findings.

The third research question also asks if there is a statistically significant relationship between the subjective burden reported by primary caregivers of incontinent dependent elderly and formal social support as a mediator of the stressor 'incontinence'. Caregivers were questioned about whether they were currently using the available

community support services that assist in dealing with incontinence. The particular services included in this list were financial assistance with incontinence supplies, bath assistance for the care receiver, laundry assistance, and aide assistance for the care receiver. Using Pearson correlation there was no significant association between burden and whether the caregiver and/or care receiver did or did not receive these services (Table 10).

Table 10
Correlation Between Burden Interview Summed Score and Formal Support(n=43)

	Correlation	R-squared
Financial assistance with incontinence supplies	-.122	.015
Regular bath assistance for CR	.135	.018
Regular laundry assistance	.075	.006
Regular paid aide for CR	.041	.002

Note. CG = caregiver; CR = care receiver; no significant findings.

Summary. In summary, the results of this study indicate that in this group of caregivers there is no association demonstrated between the caregiver's perception of burden and objective indicators of the stressor incontinence; the stressors present in the caregiving role identified as cognitive impairment in the care receiver and functional disability and difficulty in self care of the care receiver; and the formal or informal social support the caregiver received to manage the care receiver's incontinence. There is some indication that the caregiver's appraisal of the stressor 'incontinence' may be related to the perceived burden, but the direction of this association is not clear. Does the higher level of perceived burden being experienced by the caregiver affect their appraisal

of the incontinence or does the caregiver's appraisal of the incontinence lead to the higher level of perceived burden? This supports the theoretical arguement put forth by Zarit (1992) that there are subjective attributes to primary objective stressors, one of which is incontinence. These subjective attributes are the extent to which individual caregivers perceive the stressor to be disturbing, threatening, overwhelming, or manageable and as such affect the caregiver's perception of burden related to that stressor. This finding does not rule out the possibility that a caregiver experiencing greater burden will not perceive any stressor identifiable as disturbing, threatening, or overwhelming. The only contextual feature identified as being associated with the caregiver's perception of burden is the caregiver's self rating of their own health. The analysis of the data supported by the researcher's field notes indicated that those caregivers who reported poor health were experiencing higher levels of perceived burden.

Discussion

Relationship Between Caregiver Burden and Care Receiver Incontinence

Using the framework for caregiving proposed by Zarit (1992) and the Burden Interview (Zarit & Zarit, 1983) there was no significant relationship demonstrated between perceived caregiver burden and most of the aspects of care receiver incontinence that were investigated. These included length of time care receiver has been incontinent, frequency of incontinence, amount of incontinence, amount of assistance care receiver requires to manage incontinence, changes over time, feelings about the incontinence, amount of informal assistance, and amount of formal assistance. Those caregivers who indicated that their feelings toward the care receiver had changed due to the incontinence were reporting higher levels of burden, indicating that the caregiver's subjective appraisal of incontinence may be related to perceived burden. There was some indication that those caregiver's with higher levels of perceived burden were considering the care receiver's incontinence in their decision to continue caregiving. Those caregivers who were experiencing higher levels of burden indicated more frequently that incontinence may play a part in a decision to discontinue their caregiving role. It was not clear whether the higher level of perceived burden was associated with the care receiver's incontinence or the higher level of burden the caregiver was experiencing was causing them to appraise the incontinence more negatively.

Past studies have identified urinary incontinence as being one of the objective stressors associated with increased levels of perceived burden in caregivers (Baines, 1984; Brink, Wells & Diokno, 1983; Chenoweth & Spencer, 1986; Given, King, Collins & Given, 1988; Heller, Whitehead & Johnson, 1989; Jones & Vetter, 1984; Noelker, 1987; Noelker & Bass, 1989; Schirm, 1989; Snyder & Keefe, 1985; Zarit, Todd & Zarit, 1986). In these instances incontinence was identified as a factor in the caregiving situation that was present in situations where the caregiver was reporting higher levels of perceived burden.

This study identified those caregivers who were dealing with incontinence in the care receiver and attempted to identify specific factors in relation to the experience of caring for an incontintent care receiver that influence the level of reported caregiver burden.

Incontinence was a factor in all the cargiving situations. None of the variables that measured objective indicators of care receiver incontinence was significantly associated with perceived burden in those caregivers providing care to incontinent care receivers revealed a significant association with perceived caregiver burden. In this sample 65% of the caregivers reported moderate to severe levels of burden. It appears that there were other factors besides the care receiver's incontinence that were related to these increased levels of perceived burden. The care receiver's incontinence, although possibly contributing to perceived burden, is not a major factor.

There was some indication that the caregiver's subjective appraisal of the care receiver's incontinence may be associated with burden. Those caregivers who stated their feelings about the care receiver were changed as a result of the incontinence reported higher burden. Zarit (1992) states that subjective attributes of the stressor reflect individual differences in the meaning of the behaviors and in the appraisal of threat from specific care events. It would appear that it is not dealing with the incontinence itself but how the caregiver views the incontinence which is more important. This knowledge may have implications when considering possible interventions.

Research Limitations. In reviewing the study the researcher identified a number of limitations, the implications of which may have affected the findings. The first of these is sampling bias. By using a volunteer sample, where only those caregivers who are caring for incontinent care receivers and are willing to be interviewed participate, the researcher may not have gained access to those caregivers for whom caring for an incontinent care receiver is perceived as a burden. Zarit (1992) stated that although self-selection may introduce particular biases into a sample, it is not necessarily troublesome for intervention studies or for research that focuses on subsets of caregivers with certain characteristics. In this instance all the caregivers interviewed were dealing with the incontinence in the caregiving situation.

A second limitation is that of sample size. The study as initially proposed was intended to sample 100 caregivers. This was reduced as a result of subject availibility and time factors after determining that those caregivers interviewed to date did not vary substantially. It was

anticipated that increasing the numbers in the sample within the parameters defined by the study would not substantially affect the results obtained.

A third possible limitation identified by the researcher is the use of this measurement tool to look at a single characteristic which has been associated with increased burden. The Burden Interview (Zarit & Zarit, 1983) has been used as a instrument in many studies to identify significant associations between perceived caregiver burden and a number of care receiver characteristics, including care receiver incontinence. It has not been used to look at the specifics of the individual care receiver characteristics that have been so identified. Although the caregivers interviewed were reporting moderate to severe levels of burden, in this sample this did not appear to be significantly associated with incontinence or any identified aspect of incontinence. Given the response of the caregivers to the questions related to incontinence it appears to be more likely that in this group of caregivers incontinence in the care receiver was not significantly contributing to perceived burden.

Summary. Incontinence is a common problem in community dwelling dependent elderly, the incidence of which increases with age and degree of disability in the care receiver. This study suggests that it is other behavioral symptoms or caregiving concerns that are contributing to the perception of caregiver burden. The issues of concern most frequently identified in the group of caregivers interviewed were not the care receiver's incontinence but the maintenance of the caregiver's health so that they would be able to continue providing care, and the possibly related issues of adequate rest and respite. This conclusion would be supported by two recent studies looking at a similar topic. Ouslander, Zarit, Orr & Muira (1990), looked at 184 caregivers of community-residing dementia patients to determine the prevalence of urinary incontinence as reported by caregivers in this population, to identify how it was being evaluated and managed, and to assess its contribution to stress among caregivers. They found that incontinence is a common problem in this population but that the overall frequency of other behavioral symptoms and the quality of the prior caregiver-care receiver relationship were more strongly associated with caregiver burden than

urinary incontinence. As with the present study, it may be that the caregivers appraisal of the stressor incontinence, rather then the behavior itself, is associated with caregiver burden. Using the responses from 148 returned questionnaires Flaherty, Miller & Coe (1992) examined the burden imposed by urinary incontinence compared with the burden associated with other care-receiver dependencies; factors associated with perceived urinary function burden; and the relative contribution of urinary function burden to caregivers' symptoms of depression or an adverse change in health since the beginning of caregiving. Although not definitive, they found that reasons for urinary function burden differ depending on the urinary incontinence status of the care receiver. This study recommended that the impact of urinary incontinence on caregiver stress needs to consider the influence of time and duration of caregiving effort and care receiver mobility, again supporting the statement that the urinary incontinence is not in itself the factor creating the increased caregiver burden.

Relationship Between Care Receiver Incontinence and Institutionalization of Care Receiver

Past studies have associated care receiver incontinence with the decision to institutionalize the care receiver (Chenoweth & Spencer, 1986; Forbes, Jackson & Kraus, 1987; Hu, 1990; Knopman, Kitto, Deinard, & Heiring, 1988; Lund, Pett & Caserta, 1987; O'Donnell, Drachman, Barnes, Peterson, Swearer & Lew, 1992; Smallegan, 1985; Worcester & Quayhagen, 1983; Zarit, Todd & Zarit, 1986). In the group of caregivers interviewed for this study this association was not supported. Those caregivers who were presently caring for the care receiver at home did not see urinary incontinence as a reason to institutionalize the care receiver. When asked if they felt unable to care for the care receiver any longer because of the incontinence 38 (88%) of the caregivers interviewed stated they never felt that way. This statement would be supported by other findings related to the length of time care receivers have been incontinent and requiring the assistance of the caregiver. It was noted however that those caregivers who report the most burden have a positive correlation ($r = .42$, $p < .01$) with the question concerning their ability to continue caring for the care receiver any longer because of their incontinence. These findings are consistent

with those of Ouslander, Zarit, Orr & Muira (1990) who found that in a community-dwelling population of older dementia patients in whom severe cognitive impairments and disruptive behaviors are common, incontinence does not play a major role in overall burden perceived by caregivers but it may eventually contribute to the decision to institutionalize the care receiver.

In those caregiving situations where the care receiver has been institutionalized either part-time or fulltime within the past year, incontinence was not cited by a single caregiver as a factor in that decision. Caregiver health, physical and emotional inability to continue providing the required level of care, and lack of support to maintain the care receiver at home with an increasing level of disability were the reasons given by the caregivers interviewed. A description of 2 caregiving situations encountered by the researcher will serve to illustrate.

In the first situation the care receiver is an 80 year old man who has Parkinson's Disease and Alzheimers Disease which required him to retire from farming in 1978. The caregiver is his 77 year old wife. They moved to an apartment in the city in 1978 and a lodge in 1989. Between 1978 and 1991 the wife cared for her husband who she described as increasingly dependent and demanding. In 1989 the caregiver had cardiac bypass surgery and in 1991 surgery for a bowel obstruction and perforation. During each of her surgeries her husband was hospitalized and returned home following her discharge. Following the second surgery she was unable to manage her husband's care at home and he was admitted to an auxiliary hospital where he remains. The caregiver expressed distress with this situation and stated several times during the interview how much she loved her husband, how hard she had tried to care for him, and how she just couldn't do anymore. Her husband had been incontinent and required increasing amounts of assistance with his incontinence over the past year prior to entering the institution. This caregiver did not cite the incontinence as a reason for the admission to auxiliary care but stated that as her own health got worse it became more difficult for her to manage the work associated with the incontinence. In this instance it would appear that as the caregiver's burden increased the incontinence became a factor in the decision to institutionalize the care receiver.

In the second situation the care receiver is a 71 year old woman who suffered a stroke 18 months previously, is confined to a wheelchair, and has been incontinent since that time. She is totally dependent for dressing, bathing, toileting, and mobility. For 5 months following the stroke she was cared for at home by her 70 year old husband. He had built aids to assist her following her stroke which included ramps and a commode as there was no bathroom facilities on the main level of their home and she could not negotiate the stairs. During this time he washed her at the kitchen sink. After this 5 months they jointly decided that she would enter a nursing home. The caregiver speaks with her daily, visits her during the week, and brings her home each weekend from Firday till Sunday evening. It was concern for his health and the fact that if he was sick he could not help her that prompted their decision. This caregiver was very open in talking about his wife's incontinence and was very emphatic in stating that it had not changed his feelings toward his wife or been a factor in their decision to have her enter a nursing home.

Caregiving and the Maintenance of Caregiver Health

In looking at those items in the Burden Interview which were of more concern to the caregivers interviewed and the field notes made by the researcher following each interview, the major issue of concern for many caregivers in this sample was the maintenance of their own health. Caregivers perceived their health to be the key in their continued ability to provide care and support to care receivers who were identified by them as very dependent. This was further supported by the finding that those caregivers who rated their health as fair or poor were experiencing higher levels of perceived burden ($r = .41$, $p < .01$). Related to this are concerns expressed by the caregivers about interrupted nights, access to respite, and getting a break.

An expressed concern of many caregivers, especially in the spousal caregiving situation, was the maintenance of their own health so that they could continue to care for the dependent care receiver. Their ability to provide this care was seen by them as the only thing standing between the care receiver being at home and being institutionalized. A description of 4 caregiving situations encountered in this sample serves to illustrate the reality of this concern.

In the first situation the care receiver is an 82 year old male who is bedridden following a stroke 7 years ago. He is totally dependent on his 81 year old spouse for all his personal care needs: eating, dressing, bathing, et cetera. This has been the case for the past 7 years. He has been incontinent since his stroke. The caregiver in this situation receives the assistance of a personal care aide for 6 hours per day, 5 days per week and manages her husband's care alone the remainder of the time. If her health fails and she should be unable to provide this care her husband would require institutional placement. The caregiver stated that the placement authority has rated her husband as requiring an auxiliary level of care.

In the second situation the care receiver is a 67 year old female who suffered a stroke 4 years ago. She has been aphasic, hemiplegic, and incontinent since that time and is totally dependent on her 57 year old husband. This care receiver attends a dependent adult day care program for 6 hours per day, 2 days per week. Other then this time the caregiver manages his wife's care unassisted. Several times during the interview he expressed concern about what would happen to her should be be unable to look after her.

In the third situation the care receiver is an 88 year old male. He is a frail gentleman who has been incontinent for 6 years since prostate surgery. Six months ago he suffered a stroke and pneumonia and has required increasing amounts of assistance since that time. He is totally dependent on his frail 79 year old wife. This caregiver was receiving physiotherapy for rehabilitation related to a broken arm up until her husband's stroke but is no longer able to as she feels she cannot leave him alone. She is supported with light housekeeping assistance on a biweekly basis and the care receiver attends a geriatric day hospital program 2 days per week. This caregiver stated her commitment to caring for her husband as long as she is physically able and has to date refused two different placement opportunities.

In the fourth situation the care receiver is a 74 year old male. He has been diagnosed as having Parkinson's disease, is confined to a wheelchair, is totally dependent for all of his personal care needs, and cannot be left alone unsupervised. He has had retention with overflow incontinence requiring intermittent catheterization for 17 years. This

was originally managed independently but has been a caregiver responsibility for 3 years. The caregiver in this instance is a 67 year old spouse of 15 years. To support this couple the care receiver attends a dependent adult day care program for 6 hours per day, 2 days per week, receives bath assistance 2 times per week, and homemaking assistance for 6 hours per week. Other then this the caregiver manages her husband's care unassisted. She has stated a commitment to caring for her husband as long as she is physically able, relating that he was in hospital for placement assessment but she brought him home because she felt she could care for him better.

In the case of those caregivers interviewed who had arranged for the care receiver to be institutionalized either full or part time during the past year, caregiver health was the factor that was cited most frequently as contributing to this event. A description of 2 situations related by the caregivers interviewed will serve to illustrate this.

In the first situation the care receiver is 78 year old man, husband of the the caregiver, who had been admitted to auxiliary placement 1 month prior to the interview. The care receiver had a history of Alzheimer's disease which and had deteriorated rapidly over the preceding 6 months. He had a history of urgency and urinary incontinence for several years with increasing dependence on his wife in relation to this. He had been totally incontinent for the 6 months prior to institutionalization. The caregiver, 75 years old and married to the care receiver for 53 years is distressed at no longer being able to manage her husband's care. She stated that had she been able to get adequate rest at night and her husband been cooperative she would have continued to care for him at home even though he was confused, and incontinent. In the six months prior to his admission to auxiliary care he became resistive and combative requiring two persons to dress and undress him, was up wandering throughout the night, and was totally incontinent refusing to wear any protection. The caregiver had lost 25 pounds and stated she just couldn't manage any longer. She further stated that although the care receiver's incontinence was a serious problem to her, this was because of his refusal to wear protection and physical resistance to changing and going to the bathroom. She further stated that when the care receiver was cooperative the incontinence was not a problem.

Incontinence was not the primary reason for her decision to admit him to auxiliary care.

In the second instance the care receiver is an 81 year old lady who was admitted to and nursing home 3 months prior to the interview. She has a history of Alzheimer's disease. She fell and broke her hip 6 months prior to entering the nursing home. She had been incontinent 2-3 times per week prior to the hip surgery and was incontinent several times daily and during the the night following her return home after this surgery. Her husband attributed this to her difficulty in mobilizing to the bathroom. The caregiver, 72 year old husband of the care receiver, was totally alone in provide care to his wife apart from the 3 months immediatly prior to her entering the nursing home when he had aide assistance for 2 hours per day. He is a frail gentleman in obviously ill health having lost 40 pounds over the past few months and been diagnosed with untreatable cancer. He stated that he cared for his wife as long as he could but his health didn't allow him to continue and he wanted to make sure she was settled in a place of his choosing should anything happen to him. He was visibly upset that his wife requires care and he feels he cannot provide it. Although he found his wife's increasing incontinence distressing he stated that he was more then willing to 'put up with it' and would not have considered it a reason to discontinue his caregiving.

Possibly related to maintenance of caregiver health are the caregiver's expressed concerns about inadequate rest due to being up at night with the care receiver, never being able to get away to do things for themself because of inability or unwillingness to leave the care receiver alone for any length of time, and the desire for a break or holiday from time to time.

Of the 43 caregivers interviewed 26 were consistently up a minimum of once per night with the care receiver. Often this night time care was the giving of assistance in relation to the care receiver's incontinence. The caregivers who have institutionalized the care receiver either fulltime or part-time stated that this was factor in their decision. They stated that it was not the care receiver being incontinent that led to the decision but the inability to get any rest. They spoke of being too tired and worn out to continue carrying on day and night unassisted.

In one instance the 65 year old spouse of a 71 year old described caring for her husband since a 1981 stroke through a series of health related complications of diabetes. These included congestive heart failure and a double leg amputation in 1989. Homecare assistance consistied of a weekly bath and a daily sponge and shave. She cared for him during the day and was up 3-4 times per night to assist him. The care receiver made the decision to enter an auxiliary hospital 2 months prior to the interview against the caregiver's expressed wishes. He continues to come home overnight on weekends. The caregiver stated that only since that time has she come to realize how tired she was. A chronically sore back and shoulder have completely resolved and she no longer feels fatigued all the time.

In another situation both wife and daughter care for a 75 year old care receiver who suffered a stroke 5 years ago and a broken hip from a fall 2 years ago. At least once per night one of them is required to get up, change the care receiver and change to bed. Usually this is the wife but both stated that the relief provided by the daughter doing this occasionally, or even knowing that someone else was available to do it, prevented exhaustion and made it easier to continue.

In a third case a 78 year old wife describes the change in night time care of her 79 year old husband. This frail gentleman has a degenerative neurological problem and prostate cancer. He requires assistance with dressing, bathing, toileting, and personal care. For the past 5 years the wife has dealt with incontinence that presented as constant dribbling. She would be up 3-4 times per night to change her husband. For the past 4 months she has been doing intermittent catheterization 5 times per day and once at around 0300 hours. She stated that the extra rest gained by only being up once during the night has made a considerable difference to her feeling of well being.

Related to caregiver health but unrelated to care receiver incontinence is the last concern expressed by a number of caregivers who were interviewed. The concern expressed is the inability to get out or get a break from the routine of fulltime caregiving due to care receiver dependence. This supports the findings of many other studies in the caregiving literature (Caserta, Lund, Wright & Redburn, 1987; Fengler & Goodrich, 1979; George & Gwyther, 1986; Haley, Levin, Brown &

Bartolucci, 1987; Morycz, 1985; Robinson, 1989; Scott, Roberto, Hutton, 1986; Teresi, Holmes, Holmes, Bergman, King & Bentur, 1989; Teresi, Toner, Bennett & Wilder, 1989; Vitaliano, Maiuro, Ochs & Russo, 1989; Zarit, Reever & Bach-Peterson, 1980).

Relationship of Findings to Framework

Using Zarit's (1992) expanded frameword for caregiving (Figure1) the researcher examined the relationship between caregiver burden and care receiver incontinence (Figure 2). Findings from this research are reflected in a revised operational model (Figure 3):

1. Caregiver's subjective appraisal of the stressor incontinence may be related to higher burden or higher levels of burden may influence the caregiver's subjective appraisal of incontinence.
2. Caregivers experiencing higher levels of burden may be more likely to consider incontinence as a factor in their decision to institutionalize the care receiver.
3. One contextual feature, caregiver health, is associated with higher burden and possibly the decision to institutionalize the care receiver.
4. Objective indicators of incontinence, social support as a mediator of the burden associated with incontinence, and contextual features of the caregiving situation other then caregiver health were not associated with caregiver burden.

This study provides support for some of the elements in Zarit's (1992) proposed framework for caregiving and neither supports nor refutes the other elements (Figure 4). As Zarit (1992) indicated, it proved useful in guiding the researcher in terms of which constructs to incorporate into the research plan and how to organize them. The results of the study can be used to add to the body of knowledge concerning the relationship of incontinence to caregiver burden and institutionalization of the care receiver.

Implications for Nursing and Future Research

What knowledge can health care professionals gain from this study? The literature states that incontinence is a common problem in dependent elderly who live in the community. Findings from this study suggest that with the support currently being provided by the

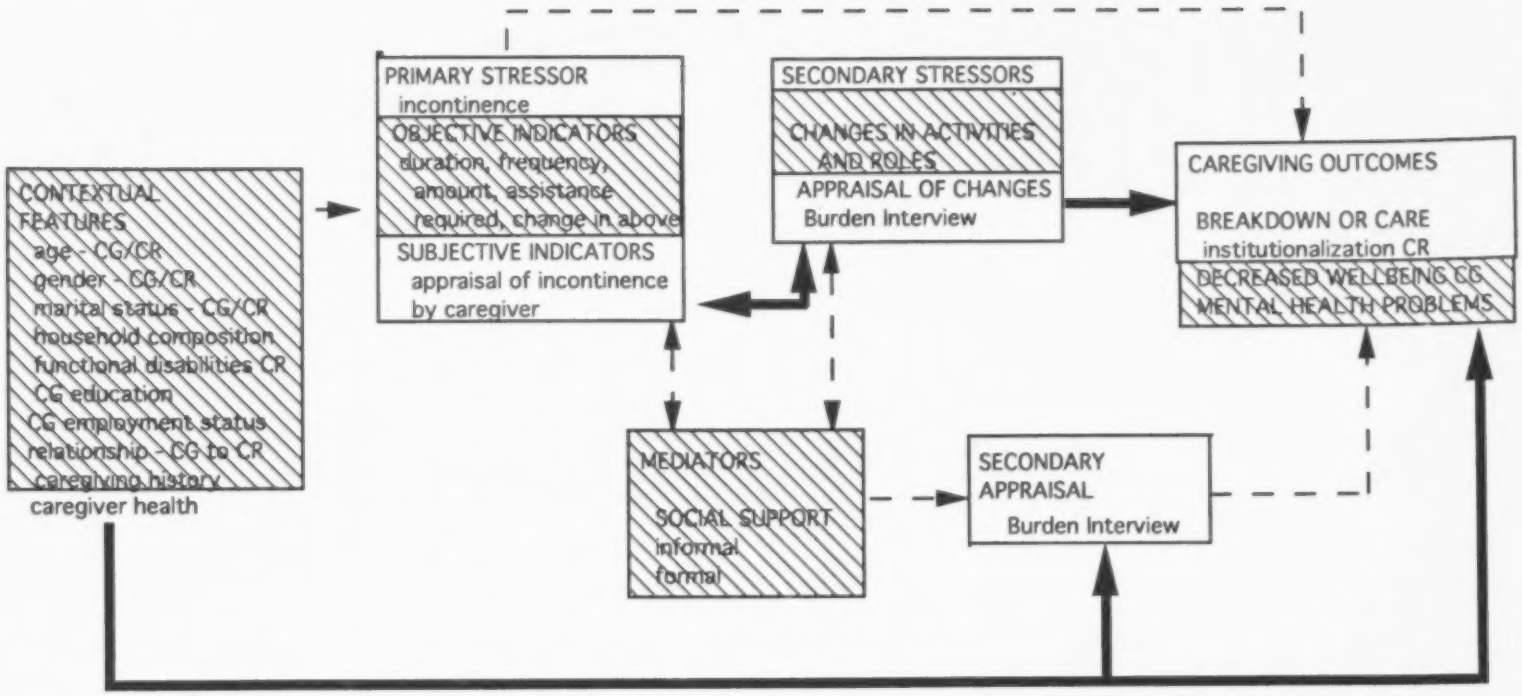

Figure 3
Operational framework indicating where research supports
Zarit's (1992) Expanded Framework for Caregiving
(unshaded areas)

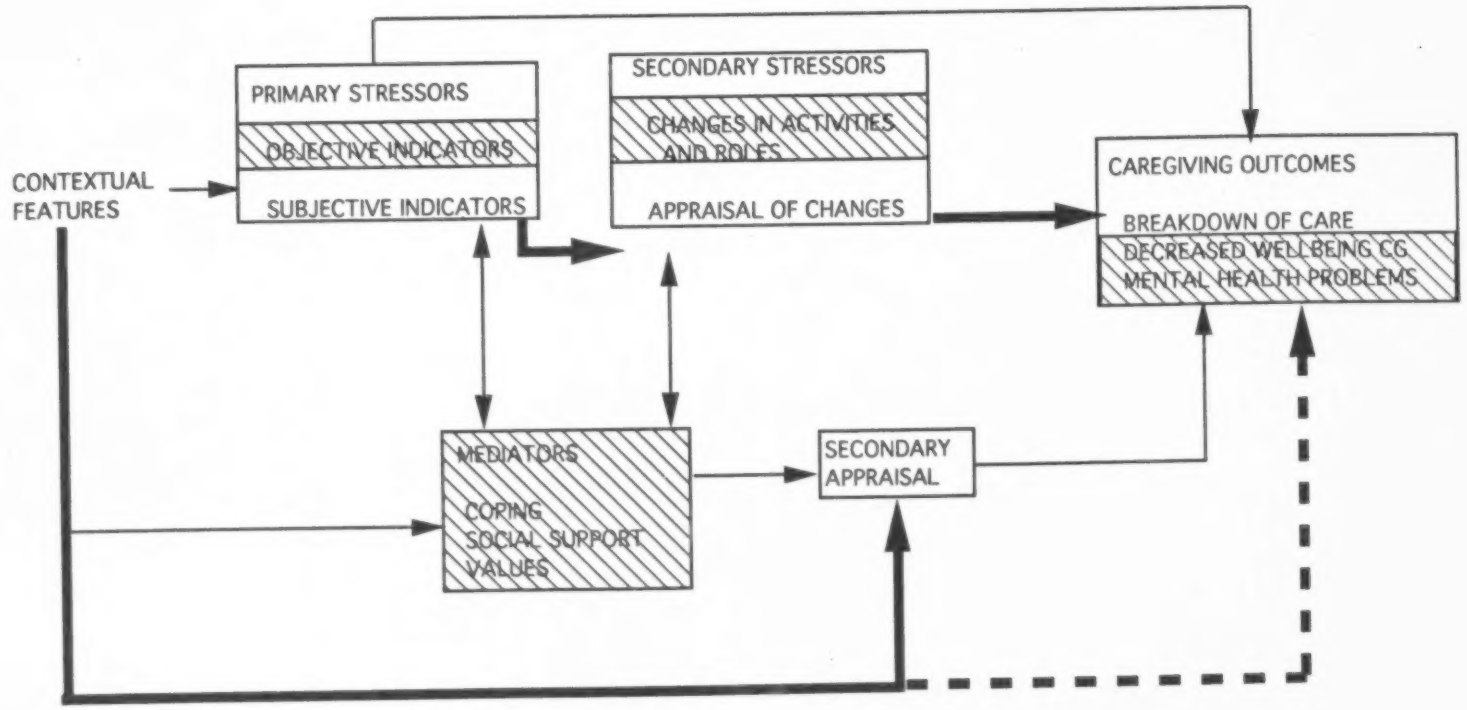

Figure 4
Theoretical framework indicating where research supports
Zarit's (1992) Expanded Framework for Caregiving
(unshaded areas)

community, those caregivers who are committed to caring for their relatives at home will not be deterred from this by care receiver incontinence. It is in relation to the caregivers subjective appraisal of incontinence as a burden that health care professionals may have the most impact. If we as health care professionals portray incontinence as manageable in the home care situation, a care event for which there is support available, and follow-up with both information and support, it is possible that we will have a positive impact on the caregiver's perception of incontinence as a burden. Although incontinence is only one of many constructs associated with caregiver burden it may be a feature of the caregiving situation where intervention would assist families and modify the overall situation in a positive way. In advising caregivers about incontinence in this population it is important that the cause of the incontinence be investigated and treated if possible. Only after this should caregivers resort to the continuing use of nonspecific supportive treatments such as absorbent garments. Educational efforts on the management of incontinence that are specifically directed at caregivers may be helpful in reducing the perceived burden experienced by these caregivers and in reducing the complications of incontinence.

What are potential areas for future investigation and research? Given the possibly biased sample identified by the researcher the most obvious area for future research is in expanding the sample studied to include a broader cross section of caregivers and care receivers. This broader cross section could include caregivers of elderly who are not incontinent, caregivers of elderly who are incontinent but able to manage their incontinence independently, caregivers of elderly who are incontinent and unable to manage their incontinence independently, and caregivers of elderly both continent and incontinent who have recently entered an institutional care setting. A longitudinal design in which caregivers were contacted on multiple occassions over a period of time may also serve to provide more understanding on whether incontinence is related to caregiver burden and what aspects of it may be of particular importance.

Other areas for future research that are suggested by the findings of this study include: the relationship between care receiver nocturia, caregiver health, and caregiver burden; and the relationship of caregiver

health to caregiver burden and institutionalization of dependent care receivers.

Summary and conclusions

In this study, the major findings in relation to the care of incontinent dependent elderly at home are as follows:

1. Although this group of caregivers are moderately to severely burdened by their caregiving responsibilities, there is no objective indicator of the care receiver's incontinence that can be significantly related to the perceived burden of the caregivers.

2. The subjective indicators of incontinence, whether the caregiver views the incontinence as manageable or distressing and overwhelming, may have more association with burden then any of the objective indicators or the support the caregiver receives.

3. The caregivers in this study did not see incontinence as a "serious problem" or consider it a reason to institutionalize the care receiver but it may play a role in the decision to institutionalize as the level of perceived burden being experienced by the caregiver increases.

4. The incontinence of the care receiver and their dependence on the caregivers to manage this incontinence had not changed the feelings of the caregiver in relation to the care receiver.

5. The caregivers interviewed felt that the assistance they received in managing the care receiver's incontinence was adequate. This support was primarily in the provision of incontinence supplies and bath assistance. Some indicated that recent changes in funding had imposed a financial burden on them.

6. Caregivers indicated that their decision to continue providing care to the care receiver was more dependent on the maintenance of their own health than on any particular care receiver problem.

7. Maintenance of caregivers health and their ability to continue providing care may be related to the caregiver obtaining adequate rest and respite. This ability to obtain adequate rest and respite may be affected by care receiver behaviors related to incontinence such as nocturia, or caregiver decisions related to incontinence such as an unwillingness to leave the care receiver alone or in the care of others.

Because of the small sample and possibility of sampling bias, the data and findings must be interpreted with caution. The findings reported

cannot be readily generalized to other populations. However, the findings are not inconsistent with the findings of other studies reporting on similar populations and may be useful in adding to the body of information about caregiver burden and incontinence.

In this study caring for an incontinent individual was not considered a burden by most caregivers, but neither was it a trivial thing. Nursing services that are provided to these individuals should reflect a relationship that understands this client perspective. By establishing a client and health professional partnership, this issue can be acknowledged and assistance individually designed to meet the needs of the caregiver and care receiver. The challenge for the health care professional is to provide assistance that supports and promotes the independence of the caregiver, both to provide care and make caregiving decisions.

References

Alberta Health. (1989). Alberta Assessment and Placement Instrument for Long Term Care (AAPI). Author.

Anthony-Bergstone, C.R., Zarit, S.H. & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. Psychology and Aging, 3(3), 245-248.

Baille, V., Norbeck, J.S. & Baines, L.E.A. (1988). Stress, social support and psychological distress of family caregivers of the elderly. Nursing Research, 37(4), 217-222.

Baines, E. (1984). Caregiver stress in the older adult. Journal of Community Health Nursing, 1(14), 257-263.

Bass, D.M., Tausig, M.B. & Noelker, L.S. (1988-89). Elder impairment, social support and caregiver strain: A framework for understanding supports effects. The Journal of Applied Social Sciences, 13(1), 80-117.

Birkel, R.C. (1987). Toward a social ecology of the home-care household. Psychology and Aging, 2(3), 294-301.

Brink, C., Wells, T. & Diokno, A. (1983). A continence clinic for the aged. Journal of Gerontological Nursing, 9(12), 651-655.

Brink, P.G. & Wood, M.J. (1988). Basic steps in planning nursing research. Boston, MA: Jones and Bartlett.

Brody, E.M. (1989). The family at risk. In E. Light & B.D. Lebowitz (Eds.), Alzheimer's disease, treatment and family stress: Directions for research (pp. 2-49). Washington, DC: National Institute of Mental Health.

Bunting, S.M. (1989). Stress on caregivers of the elderly. Advances in Nursing Science, 11(2), 63-73.

Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. Gerontologist, 23(6), 597-604.

Caserta, M.S., Lund, D.A., Wright, S.C. & Redburn, D.E. (1987). Caregivers to dementia patients: The utilization of community services. The Gerontologist, 27(2), 209-214.

Chenoweth, B. & Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist, 26(3), 267-272.

Colerick, E.J. & George, L.K. (1986). Predictors of institutionalization among caregivers of patients with Alzheimer's disease. Journal of the American Geriatrics Society, 34(7), 493-498.

Crichton, A. & Hsu, D. (1990). Canada's health care system: Its funding and organization. Ottawa, Ont: Canadian Hospital Association.

Deimling, G.T. & Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology, 41(6), 778-784.

Deimling, G.T. & Poulshock, S.W. (1985). The transition from family in-home care to institutional care. Research on Aging, 7(4), 563-576.

Deimling, G.T., Bass, D.M., Townsend, A.L. & Noelker, L.S. (1989). Care related stress: A comparison of spouse and adult-child caregivers in shared and separate households. Journal of Aging and Health, 1(1), 67-82.

Derogatis, L.R., Lipman, R.S., Covi, L., Richels, K. & Uhlenhuth, E.R. (1970). Dimensions of outpatient neurotic pathology: Comparison of a clinical versus and empirical assessment. Journal of Consulting and Clinical Psychology, 34, 164-171.

Diokno, A.C., Brock, B.M., Brown, M.B. & Herzog, A.R. (1986). Prevalence of urinary incontinence and other urological symptoms in the noninstitutionalized elderly. Journal of Urology, 136, 1022-1025.

Dobson, P. (1974). Management of incontinence in the home: A survey. London: The Disabled Living Foundation.

Fengler, A.P. & Goodrich, N. (1979). Wives of elderly disabled men: The hidden patients. Gerontologist, 19(2), 175-183.

Fillenbaum, G.C. (1988). Multidimensional functional assessment of older adults: The Duke older americans resources and services procedures. Hillsdale, NJ: Lawrence Erlbaum Associates.

Fitting, M., Rabins, P., Lucas, M.J. & Eastham, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. The Gerontologist, 26(3), 248-252.

Flaherty, J.H., Miller, D.K., & Coe, R.M. (1992). Impact on caregivers of supporting urinary function in noninstitutionalized, chronically ill seniors. The Gerontologist, 32(4), 541-545.

Forbes, W.F., Jackson, J.A. & Kraus, A.S. (1987). Institutionalization of the elderly in Canada. Toronto: Butterworths.

Gallagher, D., Rappaport, M., Benedict, A., Lovett, S. & Silven, D. (1985). Reliability of selected interview and self-report measures with family caregivers. Paper presented at the meetings of the Gerontological Society of America, New Orleans, LA.

Gallagher, D., Wrabetz, A., Lovett, S., Del Maestro, S. & Rose, J. (1989). Depression and other negative affects in family caregivers. In E. Light & B.D. Lebowitz (Eds.), Alzheimer's disease, treatment and family stress: Directions for research (pp. 218-244). Washington, DC: National Institute of Mental Health.

Gatz, M., Bengtson, V.L. & Blum, M.J. (1990). Caregiving families. In J.E. Birren & K.W. Schaie (Eds.), Handbook of the psychology of aging (pp. 404-426). San Diego, CA: Academic Press Inc.

George, L.K. & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26(3), 253-259.

Gilleard, C.J., Belford, H., Gilleard, E., Whittick, J.E. & Gledhill, K. (1984). Emotional distress amongst the supporters of the elderly mentally infirm. British Journal of Psychiatry, 145, 172-177.

Given, B.A., King, S.K., Collins, C. & Given, C.W. (1988). Family caregivers of the elderly: Involvement and reactions to care. Archives of Psychiatric Nursing, 11(5), 281-288.

Glass, G.V. & Hopkins, K.D. (1984). Statistical methods in education and psychology (2nd ed.). Englewood Cliffs,NJ: Prentice-Hall.

Gonyea, J.G. (1987). The family and dependency: Factors associated with institutional decision-making. Journal of Gerontological Social Work, 10(1-2), 61-77.

Haley, W.E., Levine, E.G., Brown, S.L. & Bartolucci, A.A. (1987). Stress, appraisal, coping and social support as predictors of adaptational outcome among dementia caregivers. Psychology and Aging, 2(4), 323-330.

Harris, T. (1986). Aging in the eighties: Prevalence and impact of urinary problems in individuals age 65 years and over (Report No. 86-1250). Hyattsville, MD: Public Health Service.

Hasselkus, B.R. (1987). Family caregivers for the elderly at home: An ethnography of meaning and informal learning. Unpublished doctoral dissertation, University of Wisconsin, Madison.

Hasselkus, B.R. (1989). The meaning of daily activity in family caregiving for the elderly. The American Journal of Occupational Health, 43(10), 649-656.

Hassinger, M.J. (1985). Community-dwelling dementia patients whose relatives sought counselling services regarding patient care: Predictors of institutionalization over a one-year follow-up period. Unpublished doctoral dissertation, University of Southern California.

Heller, B.R., Whitehead, W.E. & Johnson, L.D. (1989). Incontinence. Journal of Gerontological Nursing, 15(5), 16-23.

Herzog, A.R. & Fultz, N.H. (1990). Prevalence and incidence of urinary incontinence in community-dwelling populations. Journal of the American Geriatrics Society, 38(3), 273-281.

Hirschfeld, M.J. (1981). Families living and coping with the cognitive impaired. In L.A. Copp (Ed.), Recent advances in nursing: Care of the aging (pp. 159-167). Edinburgh: Churchill Livingstone.

Hirschfeld, M.J. (1983). Homecare versus institutionalization: Family caregiving and senile brain disease. International Journal of Nursing Studies, 20(1), 23-32.

Hu, T. (1990). Impact of urinary incontinence on health-care costs. Journal of the American Geriatrics Society, 38, 292-295.

Johnson, C.H. (1983). Dyadic family relations and social support. Gerontologist, 23(4), 377-383.

Johnson C.L. & Catalano, D.J. (1983). A longitudinal study of family supports to impaired elderly. Gerontologist, 23(6), 612-618.

Jones, D.A. & Vetter, N.J. (1984). A survey of those who care for the elderly at home: Their problems and their needs. Social Science Medicine, 19(5), 511-514.

Killeen, M. (1989). Health promotion practices of family caregivers. Health Values, 13(4), 3-10.

Knopman, D.S., Kitto, J., Deinard, S. & Heiring, J. (1988). Longitudinal study of death and institutionalization in patients with primary degenerative dementia. Journal of the American Geriatrics Society, 36(2), 108-112.

Kok, A.L.M., Voorhorst, F.J., Burger, C.W., Van Houten, P., Kenemans, P. & Janssens, J. (1992). Urinary and faecal incontinence in community-residing elderly women. Age and Ageing, 21, 211-215.

Kosberg, J.I. & Cairl, R.E. (1986). The cost of care index: A case management tool for screening informal care providers. Gerontologist, 26(3), 273-278.

Lawton, M.P. & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. Gerontologist, 9, 179-186.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M. & Glicksman, A. (1989). Measuring caregiving appraisal. Journal of Gerontology, 44(3), P61-71.

Lazarus, R.S. & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer Publishing Company.

Lund, D.A., Pett, M.A. & Caserta, M.S. (1987). Institutionalizing dementia victims: Some caregiver considerations. Journal of Gerontological Social Work, 11(1/2), 119-135.

McKenzie, D.A., Capuzzi, C.F. & Will, S.J. (1989). Alberta Assessment and Placement Instrument: Description and interrater reliability. Medical Care, 27(10), 937-941.

Mohide, E.A., Pringle, D.M., Robertson, D. & Chambers, L.W. (1988). Prevalence of urinary incontinence in patients receiving home care services. Canadian Medical Association Journal, 139, 953-956.

Montgomery, R.J.V., Gonyea, J.G. & Hooyman, N.R. (1985). Caregiving and the experience of subjective and objective burden. Family relations, 34, 19-26.

Moritz, D.J., Kasl, S.V. & Berkman, L.F. (1989). The health impact of living with a cognitively impaired elderly spouse: Depressive symptoms and social functioning. Journal of Gerontology, 44(1), S17-27.

Morycz, R.C. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. Research on Aging, 7(3), 329-361.

Noelker, L.S. (1987). Incontinence in elderly cared for by family. Gerontologist, 27(2), 194-200.

Noelker, L.S. & Bass, D.M. (1989). Home care for elderly persons: Linkages between formal and informal caregivers. Journal of Gerontology, 44(2), S63-70.

Novak, M. & Guest, C. (1989). Caregiver response to Alzheimer's disease. International Journal of Aging and Human Development, 28(1), 67-79.

Nygaard, H.A. (1988). Strain on caregivers of demented elderly people living at home. Scandanavian Journal of Primary Health Care, 6, 33-37.

O'Donnell, B.F., Drachman, D.A., Barnes, H.J., Peterson, K.E., Swearer, J.M. & Lew, R.A. (1992). Incontinence and troublesome behaviors predict institutionalization in dememtia. Journal of Geriatric Psychiatry and Neurology, 5, 45-52.

Ouslander, J.G. (1992). Geriatric urinary incontinence. Disease a Month, 31, (2), 71-149.

Ouslander, J.G., Zarit, S.H., Orr, N.K. & Muira, S.A. (1990). Incontinence among elderly community-dwelling dementia patients: Characteristics, management, and impact on caregivers. Journal of the American Geriatrics Society, 38, 440-445.

Palmer, M.H. (1988). Incontinence: The magnitude of the problem. Nursing Clinics of North America, 23(1), 139-157.

Pearlin, L.I. & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior, 19, 2-21.

Pearlin, L.I., Turner, H. & Semple, S. (1989). Coping and the mediation of caregiver stress. In E. Light & B.D. Lebowitz (Eds.), Alzheimer's disease, treatment and family stress: Directions for research (pp. 198-217). Washington, DC: National Institute of Mental Health.

Pearson, J., Verma, S. & Nellett, C. (1988). Elderly psychiatric patient status and caregiver perceptions as predictors of caregiver burden. Gerontologist, 28 (1), 79-83.

Poulshock, S.W. & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39(2), 230-239.

Pratt, C., Schmall, V. & Wright, S. (1986). Family caregivers and dementia. Social Casework, 67(2), 119-124.

Pratt, C.C., Schmall, V.L., Wright, S. & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. Family Relations, 34, 27-33.

Pratt, C., Wright, S. & Schmall, V. (1987). Burden, coping and health status: A comparison of family caregivers to community dwelling and institutionalized Alzheimer's patients. Journal of Gerontological Social Work, 10(1-2), 99-112.

Pruchno, R.A., Kleban, M.H., Michaels, J.E. & Dempsey, N.P. (1990). Mental and physical health of caregiving spouses: Development of a causal model. Journal of Gerontology, 45(5), P192-199.

Pruchno, R.A. & Resch, N.L. (1989). Aberrant behaviors and Alzheimer's disease: Mental health effects on spouse caregivers. Journal of Gerontology, 44(5), S177-182.

Pruchno, R.A. & Resch, N.L. (1989). Husbands and wives as caregivers: Antecedents of depression and burden. Gerontologist, 29(2), 159-165.

Quayhagen, M.P. & Quayhagen, M. (1988). Alzheimers stress: Coping with the caregiving role. Gerontologist, 28(3), 391-396.

Robinson, K.M. (1989). Predictors of depression among wife caregivers. Nursing Research, 38(6), 359-363.

Schirm, V. (1989). Functionally impaired elderly: Their need for home nursing care. Journal of Community Health Nursing, 6(4), 199-207.

Schulz, R., Visintainer, P. & Williamson G.M. (1990). Psychiatric and physical morbidity effects of caregiving. Journal of Gerontology, 45(5), P181-191.

Scott, J.P., Roberto, K.A. & Hutton, J.T. (1986). Families of Alzheimer's victims: Family support to the caregivers. Journal of the American Geriatrics Society, 34(5), 348-354.

Sheehan, N.W. & Nuttall, P. (1988). Conflict, emotion and personal strain among family caregivers. Family Relations, 37(1), 92-98.

Smallegan, M. (1985). There was nothing else to do: Needs for care before nursing home admission. Gerontologist, 24(4), 364-369.

Snyder, B. & Keefe, K. (1985). The unmet needs of family caregivers for frail and disabled adults. Social Work in Health Care, 10(3), 1-14.

Stephens, M.A.P., Norris, V.K., Kinney, J.M., Ritchie, S.W. & Grotz, R.C. (1988). Stressful situations in caregiving: Relations between caregiver coping and well-being. Psychology and Aging, 3(2), 208-209.

Stone, R., Cafferata, G.L. & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. Gerontologist, 27(5), 616-629.

Teasdale, T.A., Taffet, G.E., Luchi, R.J. & Adam, E. (1988). Urinary incontinence in a community-residing elderly population. Journal of the American Geriatrics Society, 36, 600-606.

Teresi, J., Holmes, D., Holmes, M., Bergman, S., King, Y. & Bentur, N. (1989). Factors relating to institutional risk among elderly members of Israeli kibbutzim. The Gerontologist, 29(2), 203-208.

Teresi, J., Toner, J., Bennett, R. & Wilder, D. (1989). Caregiver burden and long-term care planning. The Journal of Applied Social Sciences, 13(1), 192-215.

Van Ort, S. & Woodtli, A. (1989). Home health care: Providing a missing link. Journal of Gerontological Nursing, 15(9), 4-9.

Vetter, N.J., Jones, D.A. & Victor, C.R. (1981). Urinary incontinence in the elderly at home. The Lancet, 11, 1275-1277.

Vitaliano, P.P., Maiuro, R.D., Ochs, H. & Russo, J. (1989). A model of burden in caregivers of DAT patients. In E. Light & B.D. Lebowitz (Eds.), Alzheimer's disease, treatment and family stress: Directions for research (pp. 267-291). Washington, DC: National Institute of Mental Health.

Wilder, D.E., Teresi, J.A. & Bennett, R.G. (1983). Family burden and dementia. Advances in Neurology, 38, 239-251.

Williams, M.E. & Gaylord, S.A. (1990). Role of functional assessment in the evaluation of urinary incontinence. Journal of the American Geriatrics Society, 38, 296-299.

Williams, M.E. & Pannill, F.C. (1982). Urinary incontinence in the elderly: Physiology, pathophysiology, diagnosis and treatment. Annals of Internal Medicine, 97(6), 895-907.

Worcester, M.I. & Quayhagen, M.P. (1983). Correlates of caregiving satisfaction: Prerequisites to elder home care. Research in Nursing and Health, 6, 61-67.

Zarit, S.H. (1989). Issues and directions in family intervention research. In E. Light & B.D. Lebowitz (Eds.), Alzheimer's disease, treatment and family stress: Directions for research (pp. 458-486). Washington, DC: National Institute of Mental Health.

Zarit, S.H. (1992). Concepts and measures in family caregiving research. In B. Bauer (Ed.), Conceptual and Methodological Issues in Family Caregiving Research: Proceedings of the Invitational Conference on Family Caregiving Research (pp. 5-19). Toronto, Ontario, Canada: University of Toronto Press.

Zarit, S.H., Birkel, R.C. & Malonebeach, E. (1989). Spouses as caregivers: Stresses and interventions. In M.Z. Goldstein (Ed.), Family involvement in the treatment of the frail elderly (pp. 23-61). Washington, DC: American Psychiatric Press Inc.

Zarit, S.H., Orr, N.K. & Zarit, J.M. (1985). The hidden victims of Alzheimer's disease: Families under stress. New York, NY: New York University Press.

Zarit, S.H., Reeves, K.E. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20(6), 649-655.

Zarit, S.H., Todd, P.A. & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26(3), 260-266.

Zarit, S.H. & Zarit, J.M. (1983). The Memory and Behavior Problems Checklist--1987R and The Burden Interview. (Available from Steven H. Zarit & Judy M. Zarit, College of Health and Human Development, Department of Individual and Family Studies, S-110 Human Development Building, The Pennsylvania State University, University Park, PA 16802)

Zarit, S.H. & Zarit, J.M. (1982). Families under stress: Interventions for caregivers of senile dementia patients. Psychotherapy: Theory, Research and Practice, 19(4), 461-471.

Appendix A

Initial Contact Letter for Potential Subjects

Faculty of Nursing
University of Alberta
Edmonton, Alberta

My name is Kathleen Daly. I am a graduate student at the University of Alberta, in the Faculty of Nursing. I am currently working with Edmonton Home Care, to complete my studies. When the person you are caring for was assessed for home care, he/she was described as being incontinent of urine. You were named as the one who helps this person the most.

The involuntary loss of urine is something people don't like to talk about. It is a private matter, but it often has far reaching effects on daily life. At present little is known about how people feel about caring for someone who is incontinent. I am interested in learning about how you assist the person you are caring for and what your feelings and concerns related to their incontinence are. By increasing what we know about incontinence, workers in the health care field may be better able to help clients in the future.

You can help by doing a questionnaire that is about this topic. No one else will see your answers. All the results of the study will be reported without any names being used. For more information about this study please call me at 487-3239, or my Thesis Supervisor, Dr. Dana Wertenberger, Faculty of Nursing, at 492-4851.

Thankyou for taking the time to think about being in this study. Please fill out the attached card, whether you plan to fill out the questionnaire or not. Return it to your case coordinator or mail it as soon as possible.

If you decide to fill out the questionnaire I will bring it to your home at a time of your choosing. I will also answer any more questions you or the person you are caring for have.

Sincerely,

Kathleen Daly, RN, BScN
Graduate Student, Faculty of Nursing
University of Alberta

Appendix B

Caregiver Consent Form for Participation in Research Study

Caregiver Consent Form for Participation in Research Study

Title of Research: Caring for Someone Who is Incontinent

Researcher

Kathleen Daly
Master of Nursing Candidate
Faculty of Nursing
University of Alberta
Phone: 487-3239

Advisor

Dr. Dana Wertenberger
Associate Professor
Faculty of Nursing
University of Alberta
Phone: 492-4851

Purpose of the Study

The purpose of this study is to find out how caregivers feel about caring for a person who is incontinent of urine and what things might make them feel this way.

Procedure

If you agree to be in the study you will fill out a questionnaire. The questionnaire asks about the following things.

1. Some background information about you such as age and gender.
2. How you are related to the person you are caring for.
3. About the person's incontinence.
4. How you feel about the person's incontinence.
5. What help you receive in relation to the person's incontinence.

It should take about 45 minutes to finish.

Kathleen Daly will also ask you some questions about what the person you are caring for is able to do by themselves, and what they need help with.

Risks

The information obtained from this study may help nurses and other health care workers to better understand and to help those who are caring for people who are incontinent. Taking part in this study may not help you directly.

Voluntary Participation and Confidentiality

You do not have to be in this study if you do not want to be. If you take part in the study you are free to withdraw at any time. Taking part in the study or withdrawing from the study will not affect the service you receive now or in the future. If you wish to withdraw from the study simply tell Kathleen Daly.

Your name is not on any of the forms. A code number will identify you. The record of your name and code number is kept in a locked drawer. At the end of the study the record is destroyed. The information collected from the study is kept. It may be used for other educational and research purposes, after ethical approval is obtained from the appropriate places. Your name will not be included in any reports of this study, in any articles, or in talks about the study.

If you have any questions or concerns at any time, you are free to call the researcher, Kathleen Daly, or advisor, Dr. Dana Wertenberger.

Consent

I, _____, have read this information. I agree to be in the study called, Caring for Someone Who is Incontinent. I have had the opportunity to ask questions about the study and my part in it. The researcher, Kathleen Daly, has answered all my questions at this time. I have been given a copy of this consent form.

_____ _____
signature of participant date

_____
signature of researcher

Appendix C

Care Recipient Consent Form for Participation in Research Study

Care Recipient Consent Form for Participation in Research Study

Title of Research: Caring for Someone Who is Incontinent

Researcher

Kathleen Daly
Master of Nursing Candidate
Faculty of Nursing
University of Alberta
Phone: 487-3239

Advisor

Dr. Dana Wertenberger
Associate Professor
Faculty of Nursing
University of Alberta
Phone: 492-4851

Purpose of the Study

The purpose of this study is to find out how caregivers feel about caring for a person who is incontinent of urine and what things might make them feel this way.

Procedure

If you agree to be in the study Kathleen Daly will ask you some questions about what you are able to do by yourself, and what you need help with.

The person who assists you will fill out a questionnaire. The questionnaire asks about the following things.

1. Some background information about you such as age and gender.
2. How you are related to the person who assists you.
3. About your incontinence.
4. How the person who assists you feels about your incontinence.
5. What help the person who assists you receives in relation to your incontinence.

Risks

The information obtained from this study may help nurses and other health care workers to better understand and to help those who are caring for people who are incontinent. Taking part in this study may not help you directly.

Voluntary Participation and Confidentiality

You do not have to be in this study if you do not want to be. If you take part in the study you are free to withdraw at any time. Taking part in the study or withdrawing from the study will not affect the service you receive now or in the future. If you wish to withdraw from the study simply tell Kathleen Daly.

Your name is not on any of the forms. A code number will identify you. The record of your name and code number is kept in a locked drawer. At the end of the study the record is destroyed. The information collected from the study is kept. It may be used for other educational and research purposes, after ethical approval is obtained from the appropriate places. Your name will not be included in any reports of this study, in any articles, or in talks about the study.

If you have any questions or concerns at any time, you are free to call the researcher, Kathleen Daly, or advisor, Dr. Dana Wertenberger.

Consent

I, _____, have read this information. I agree to be in the study called, Caring for Someone Who is Incontinent. I have had the opportunity to ask questions about the study and my part in it. The researcher, Kathleen Daly, has answered all my questions at this time. I have been given a copy of this consent form.

_____ _____
signature of participant date

_____
signature of researcher

Appendix D

Data Collection Tool: Caregiver Burden in Relation to Incontinence in the Elderly

Data Collection Tool: Caregiver Burden in Relation to Incontinence in the Elderly

1. Age care receiver (years) ____

2. Sex care receiver

   Female [ ]

   Male [ ]

3. Marital status care receiver

   Single [ ]

   Married [ ]

   Separated [ ]

   Divorced [ ]

   Widowed [ ]

   Other (specify)_____ [ ]

4. Place of residence caregiver

   Single family dwelling [ ]

   Apartment/multi-family dwelling [ ]

   Room [ ]

   Lodge [ ]

5. Place of residence care receiver

   Single family dwelling [ ]

   Apartment/multi-family dwelling [ ]

   Room [ ]

   Lodge [ ]

6. Total number of residents including care receiver in usual residence ____

7. Do caregiver and care receiver live at same address Y N

8. Care receiver lives

With spouse only	[ ]
With spouse and others	[ ]
With others only	[ ]
With other family	[ ]
Other (specify)_____	[ ]

Activities of Daily Living		Scale 0-5
0	Independent	
1	Independent with special devices	
2	Able to manage with assistance to set up	
3	Able to manage with some sup./assistance Applicant participates	
4	Unable to manage Needs constant sup./assistance one person	
5	Unable to manage Needs constant sup./assistance two persons	
9.	Eating	____
10.	Dressing	____
11.	Grooming	____
12.	Bathing	____
13.	Toileting	____
14.	Hand care	____
15.	Foot care	____

Mobility — Scale 0-5

0 Independent
1 Independent with equipment
2 Able to manage with assistance to set up
3 Able to manage with some sup./assistance for safety and encouragement; applicant participates
4 Unable to manage, needs constant sup./ assistance of one person
5 Unable to manage, needs constant sup and/or physical support of two persons

16. Indoor ____
17. Outdoor ____
18. Stairs ____
19. Transfer ____
20. Transport ____

Activities of Household Management — Scale 0-4

0 Independent in all aspects of task
1 Independent with aids/equipment
2 Able to manage with assistance to set up
3 Able to manage with some sup./assistance
4 Unable to manage, needs constant sup./ assistance, someone else must perform the task

21. Shopping ____
22. Banking/money ____
23. Fill in forms ____
24. Meal prepartion ____
25. House cleaning/laundry ____
26. Repairs/yardwork ____

27. Awareness

Consistently responsive ____
Reduced awareness but person able to shift focus and sustain attention to environmental stimuli ____
Fluctuating awareness, not consistently able to shift focus and sustain attention to envir. stimuli ____
Consistently unresponsive due to extreme restlessness or apathy ____

28. Orientation

Oriented to person, place and time ____

Oriented to person and place ____

Oriented to person ____

Disoriented to person, place and time ____

29. Care receiver memory

Immediate, recent and remote memory intact ____
Immediate and recent memory impaired, remote generally intact ____
Immediate and recent memory impaired, some impairment in remote ____
Significant impairment in immeiate, recent and remote memory ____

30. Care receiver judgement and decicion making ability

Reality based ____

Occasionally impaired ____

Consistently impaired ____

What things do/did you find most difficult about caring for this person.

Appendix E

Questionnaire: Caring for Someone Who is Incontinent

Questionnaire

Caring for Someone Who is Incontinent

Questionnaire: Caring for Someone Who is Incontinent

General Instructions: **Please answer this questionnaire as if you were currently in the situation. For convenience, the person you are caring for will be referred to as 'your relative' throughout the questionnaire. To complete the questionnaire please check the blank beside the best answer, or fill in the blank. This is not a test and there are no right or wrong answers. The questions ask only for factual information or for your opinions and feelings. In order for the research to be complete, please answer every question.**

1. How old are you?

   _____ years of age

2. What is your sex?

   [ ] female
   [ ] male

3. What is your present marital status?

   [ ] single (never married)
   [ ] married
   [ ] separated
   [ ] divorced
   [ ] widowed
   [ ] other (specify) _____

4. How far have you gone in school?

   [ ] 0-4 years
   [ ] 5-8 years
   [ ] highschool incomplete
   [ ] highschool completed
   [ ] college or technical school
   [ ] university or undergraduate degree
   [ ] university postgraduate degree(s)

5. Which of the following best describes you at present?

   [ ] currently employed full-time outside the home
   [ ] currently employed part-time outside the home
   [ ] retired
   [ ] homemaker
   [ ] nonemployed

6. Where are you currently living?

[ ] single family dwelling
[ ] apartment/multi-family dwelling
[ ] room
[ ] lodge

7. Including yourself, how many people live in your household?

_____ people

8. Who lives with you?
Check all those that apply.

[ ] husband
[ ] wife
[ ] children
[ ] grandchildren
[ ] parent
[ ] grandparent
[ ] brother/sister
[ ] other relative
[ ] other not-related person

9. What is your relationship to the person you are caring for?

[ ] wife
[ ] husband
[ ] daughter
[ ] daughter-in-law
[ ] son
[ ] son-in-law
[ ] sister/brother
[ ] grandchild
[ ] other (specify) _____

10. How long have you had responsibility for providing care to your relative?

_____

11. How many hours per day do you provide care, supervision, or companionship to your relative?

_____ hours

12. How many times have you seen a doctor during the past 6 months about your own health? (Do not count the times you stayed overnight in the hospital.)

    _____ times

13. How many days during the past 6 months were you in hospital for health problems?

    _____ days

14. During the past 6 months, how many days were you so sick that you could not carry out your usual activities - such as working around the house or going to work?

    _____ days

15. How would you rate your overall health at the present time?

    [ ] excellent
    [ ] good
    [ ] fair
    [ ] poor

16. Is your health now better, about to same, or worse then it was a year ago?

    [ ] better
    [ ] about the same
    [ ] worse

17. How much do your health problems stand in the way of your doing the things you want to do?

    [ ] not at all
    [ ] a little (some)
    [ ] a great deal

18. How long has your relative been incontinent of urine?

    _____

19. How long has your relative required your assistance in managing their toileting and/or incontinence?

    _____

20. How often is your relative incontinent of urine?

    [ ] less than once per week
    [ ] once weekly
    [ ] 2-6 times per week
    [ ] daily
    [ ] more than once daily

21. Has the **frequency** of your relative's urinary incontinence changed from what it was 6 months ago?

    [ ] less frequent
    [ ] about the same
    [ ] more frequent

22. Has the **frequency** of your relative's urinary incontinence changed from what it was 1 year ago?

    [ ] less frequent
    [ ] about the same
    [ ] more frequent

23. How much urine is leaked out at one time when your relative is incontinent?

    [ ] a few drops
    [ ] a fair amount
    [ ] the whole bladder is emptied

24. Has the **amount** of urine your relative is incontinent of changed from what it was 6 months ago?

    [ ] less
    [ ] about the same
    [ ] more

25. Has the **amount** of urine your relative is incontinent of changed from what it was 1 year ago?

    [ ] less
    [ ] about the same
    [ ] more

26. How much help does your relative require to manage his/her urinary incontinence?

[ ] manages independently
[ ] requires assistance to get to bathroom or get equipment
[ ] requires assistance with clothing and/or transferring
[ ] unable to manage, needs constant supervision/assistance

27. Has the amount of help your relative requires in managing his/her urinary incontinence changed from what it was 6 months ago?

[ ] less help required
[ ] about the same
[ ] more help required

28. Has the amount of assistance your relative requires in managing their urinary incontinence changed from what it was 1 year ago?

[ ] less help required
[ ] about the same
[ ] more help required

29. Does your relative require help with their incontinence during the night?

[ ] less than one night per week
[ ] 2-3 nights per week
[ ] 4-6 nights per week
[ ] once per night
[ ] more than once per night

30. Has your relative's urinary incontinence ever been investigated by a doctor?

[ ] yes
[ ] no

I am interested in how you feel about helping a relative who is incontinent. Please complete the following questions as fully as possible. If there is not enough room provided, please write on the back of the paper.

31. Is your relative's incontinence

    [ ] no problem for you
    [ ] somewhat of a problem for you
    [ ] a serious problem for you

32. Please write about your feelings concerning your relative's incontinence.

_____

_____

_____

_____

_____

33. Have your feelings about your relative changed because of his/her incontinence? How have they changed?

_____

_____

_____

_____

34. What concerns you the most about your relative's incontinence?

_____

_____

_____

_____

35. Because of his/her incontinence, have you considered not caring for your relative anymore?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

36. Do you receive any help from other family members or friends in looking after your relative's incontinence?

[ ] regularly
[ ] now and then
[ ] only if I ask
[ ] rarely
[ ] never

37. Are other family members aware of your relative's incontinence?

[ ] yes
[ ] no

38. If you receive help from other family members, who provides it?

_____

_____

_____

_____

39. If you receive help from other family members, please describe the type and amount of help?

_____

_____

_____

40. Do you wish that your family would provide more help or assistance in caring for you relative's incontinence?

[ ] yes
[ ] sometimes
[ ] no

41. Do you use any of these services or resources in helping your relative with their incontinence?

[ ] financial help with incontinence supplies
[ ] help in bathing relative
[ ] help with the laundry
[ ] paid aide that helps with toileting/changing

42. If so, how often do you use these services or resources?

_____

_____

_____

_____

43. What other services do you feel would help you in looking after your relative's incontinence?

_____

_____

_____

_____

The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

44. Do you feel that your relative asks for more help than he/she needs?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

45. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

46. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

47. Do you feel embarrassed over your relative's behavior?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

48. Do you feel angry when you are around your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

49. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

50. Are you afraid of what the future holds for your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

51. Do you feel your relative is dependent upon you?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

52. Do you feel strained when you are around your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

53. Do you feel your health has suffered because of your involvement with your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

54. Do you feel that you don't have as much privacy as you would like because of your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

55. Do you feel that your social life has suffered because you are caring for your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

56. Do you feel uncomfortable having friends over because of your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

57. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

58. Do you feel that you don't have enough money to care for your relative in addition to the rest of your expenses?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

59. Do you feel that you will be unable to take care of your relative much longer?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

60. Do you feel that you have lost control of your life since your relative's illness?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

61. Do you wish you could just leave the care of your relative to someone else?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

62. Do you feel uncertain about what to do about your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

63. Do you feel you should be doing more for your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

64. Do you feel you could do a better job in caring for your relative?

[ ] never
[ ] rarely
[ ] sometimes
[ ] quite frequently
[ ] nearly always

65. Overall, how burdened do you feel in caring for your relative?

[ ] not at all
[ ] a little
[ ] moderately
[ ] quite a bit
[ ] extremely

Thankyou for filling out the questionnaire. If you are willing to have the researcher call you should she have any questions concerning the questionnaire, please add your phone number below.

Phone number: _____